



Original Research

Linking national public services data to estimate the prevalence of intellectual disabilities in The Netherlands: results from an explorative population-based study



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ABSTRACT

Objectives: Individuals with intellectual disabilities (ID) depend on public services for daily support and medical care; however, this group of individuals can be difficult to identify within population data. This therefore limits the opportunities to accurately estimate the size of the population with ID, monitor trends and tailor public health interventions according to the needs and characteristics of this group. By linking relevant databases, this study sought to identify individuals with ID in national data, to estimate the prevalence of ID based on public service use and to explore how this method can be used to better monitor the population with ID.

Study design: Explorative data linkage study using the Dutch population register and databases from public services accessible with an ID diagnosis.

Methods: The overall prevalence of ID in the Dutch adult population was estimated, specified by age group and sex, and the identified ID groups were also characterised by their support needs. Participants included the entire adult Dutch population who were alive on 1 January 2015.

Results: After linking databases, 187,149 adults with ID were identified within a population of almost 12.7 million Dutch adults, giving an ID prevalence estimate of 1.45%. Prevalence of ID was higher among males (1.7%) than females (1.2%). Most individuals with ID were identified through the use of residential care services ($n = 91,064$; 0.7%). Non-residential ID-related care was used by 27,007 individuals (0.2%). Social, employment or income support due to a (mild) ID was received by 69,078 individuals (0.5%); the mean age in these ID groups was between 8 and 10 years which is younger than that in the general Dutch population. ID prevalence declined with increasing age across all ID subgroups.

Conclusions: The ID prevalence in The Netherlands, as determined by ID-related public service usage, aligns with international estimates. This suggests that national supportive services are accessible and used by individuals with ID. Moreover, this demonstrated that databases from national supportive services can be a useful resource to identify individuals with ID at the population level and can enable structural monitoring of the ID population through linking national databases.

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Introduction

Within every population, individuals with intellectual disabilities (ID) form a specific subgroup with support needs for health, behavioural and social problems. In many countries, including The

Netherlands, these needs are met through a variety of public health and social support systems.^{1–3} Many aspects related to health and well-being, including the care and services provided through these systems, are registered as part of routine practice, either automatically or manually.⁴ These administrative data thus contain a wealth of information that could inform policy and practice about the characteristics and changes in the needs of those requesting and using these services.^{5–7} However, in many countries, it is not apparent how individuals with ID can be identified within these data or how the data can be used for monitoring purposes.^{8,9}

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For ID service providers, the infrastructure to set up data-linkages is also limited. Service providers can each have their own definition of ID, which limits opportunities to identify individuals across different databases, especially as many countries rely on multiple systems without national coverage.^{10–14} Consequently, inaccurate or incomplete identification of individuals with ID may result in findings that are neither representative nor generalisable. Such findings subsequently have limited relevance for use in policy and practice. While administrative population data have the potential to accurately identify everyone with ID, a recent review showed that ID prevalence estimates through this method still vary substantially.¹⁴

In The Netherlands, many health and social systems have national coverage and uniform procedures to collect and combine information. Regardless of which definition for ID was used to enter the supportive systems (e.g., International Classification of Diseases [ICD]-10 or Diagnostic and Statistical Manual of Mental Disorders [DSM]-V), service use and support needs are categorised the same for all individuals using these systems. Furthermore, one would expect a correlation between ID severity and the level of support requested. This allows for reproducible and consistent methods to identify the Dutch population with ID, link databases and monitor developments at the population level. However, to date, the use of these databases has been limited. To allow better use of these existing resources, this study describes a method that uniquely identifies individuals with ID by linking national databases and provides an ID prevalence estimate based on this method.

Methods

Data sources and setting

This cross-sectional study used non-public microdata, which, under certain conditions, are accessible for statistical and scientific research from Statistics Netherlands, the Dutch national statistics office.^c We took 2015 as the reference year and linked the Dutch population registry with two databases; one for chronic care and one for welfare support. Both of these databases contain information on utilisation of services accessible to individuals with ID who had formally been diagnosed by a healthcare professional according to their respective guidelines and diagnostic systems (e.g., ICD-10 or DSM-V).

The chronic care database contained information on all long-term care provided under the Chronic Care Act (CCA). The CCA regulates residential and other long-term care for people with chronic somatic conditions, vulnerable elderly people, people diagnosed with physical and/or (mild) ID or chronic mental illnesses.¹⁵ Support through the CCA can either be in-kind by pre-defined care packages for residential care (ranging from 1 to 8 depending on the level of support needs) or self-arranged for people without residential care needs.

The welfare database included information on individuals active in sheltered workplaces, recipients of unemployment or disability benefits and the reason why the provision was called upon, which could include the presence of a mild ID diagnosis. The reason Mild-ID is labelled separately in these (income-related) systems is because the definition for Mild-ID (DSM-V/ICD-10) specifies “many adults will be able to work”.^{16,17} Therefore a Mild-ID diagnosis grants access to these welfare systems, while a more severe ID diagnoses do not.

^c Procedures can be found at: <https://www.cbs.nl/en-gb/our-services/customised-services-microdata/microdata-conducting-your-own-research>, or for further information. microdata@cbs.nl.

As additional regulations apply to children aged <18 years and most of the welfare services only concerned for individuals aged ≥18 years, we restricted this study to the Dutch adult population.

The study protocol for this exploratory study was reviewed by the Radboud University Medical Center institutional Ethics Committee who passed a positive judgment and waived the need for formal ethical assessment (2017–3921). We followed the Strobe checklist for cross-sectional studies¹⁸ (see [supplemental materials A](#)).

Procedures for linkage and establishing ID groups

Before database linking was commenced, any multiple registrations of individuals within the same database were removed. Under the CCA, individuals can receive multiple entitlements within one year, resulting in multiple registrations, but only one can be active at a specific time. We therefore selected the most recent CCA registration per individual in 2015, under the assumption that it would reflect the most up-to-date support care needs. In the welfare database, individuals could simultaneously be registered as a recipient of multiple benefits, as one type of benefit could supplement another. Here, we recoded multiple records per individual into a single variable representing the combination of benefits received.

Linkage then started by retrieving sex, date of birth and a unique personal identifier (RIN number) as the primary variables from the population register containing all Dutch adults who were alive on 1 January 2015. Based on matching RIN numbers, we added information, if any, from the CCA database on entitlements to chronic care services, the type of care they were receiving and both the primary and secondary reason for which the CCA was called upon (A maximum of two reasons can be given.). Databases from the welfare systems were also linked by RIN number, which provided information about individuals entitled to benefits due to a mild ID diagnosis.

In the newly composed data set, we grouped individuals according to their support needs and degree of independence. We grouped all individuals receiving residential ID care through the CCA, regardless of any other registration, as having the greatest support needs and being least independent (residential ID group). All other individuals who called upon the CCA for any other ID-related reason and did not receive residential care were seen as having moderate support needs and being moderately independent (non-residential ID group). All individuals who had a Mild-ID diagnosis noted as their reason for accessing services in any of the databases were assumed to be the most independent ID group with the least support needs (Mild-ID). Through this classification, all individuals identified with an ID could be uniquely assigned to one of the three ID groups (i.e., residential ID group, non-residential ID group or Mild-ID). All remaining individuals who were not assigned to one of the three ID groups were assumed to be a member of the general population. A flow chart is presented in [Fig. 1](#), and the classification rules used to define groups are specified in [Supplemental materials B](#).

Statistical analyses

Demographics were presented as frequencies with percentages or means with standard deviation (SD). Age was grouped mid-decade to mid-decade (e.g., 35–44 years) following epidemiological conventions.¹⁹ ID prevalence was calculated as the number of individuals identified with ID divided by the total number of people enrolled in this study. We specified frequencies by sex and 10-year age groups and provided separate prevalence estimates per ID subgroup. As we used population data, all prevalence estimates yielded very small confidence intervals, which were considered

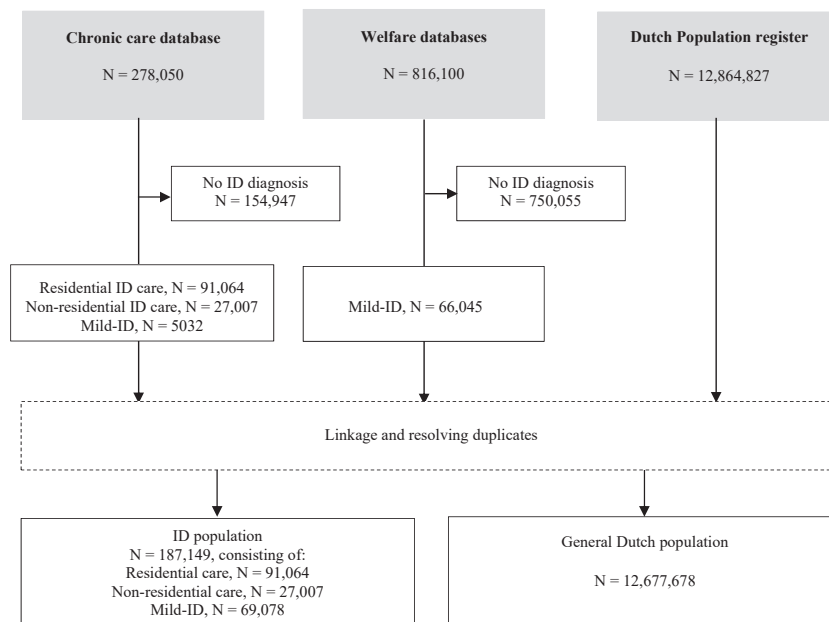


Fig. 1. Flow chart of study population. ID, intellectual disabilities.

uninformative and hence not included in the tables. Per subgroup, we used the available information to further characterise each ID subgroup separately. Analyses were conducted using SPSS (version 25.0).

Results

After linking the three databases (i.e., Dutch population registry, chronic care and welfare support databases), 187,149 individuals were identified with ID and could be assigned to one of the three ID groups based on their service use. The remaining 12,677,768 individuals were without any record of supportive ID services and were believed to form the general Dutch adult population (GenPop). Combined, the three ID groups gave an ID prevalence of 1.45% (95% confidence interval, 1.44–1.46). Mean ages across the ID groups were between 7.9 and 9.9 years which are lower (M_{age} range, 38.4–40.4 years) than those in the GenPop (M_{age} , 48.3 years). The residential care (56.0% males) and Mild-ID (63.4% males) groups contained more males than the GenPop (48.9%; Table 1). The overall ID prevalence was higher among males than females across all age groups and declined with increasing age, ranging from 3.6% for males between 18 and 24 years of age to 0.2% among females aged ≥ 75 years (Fig. 2).

Residential care

The residential care group consisted of 91,064 individuals with ID (56.0% male), with an average age of 40.3 years ($SD = 16.4$). The largest age group was the 18–24 years group (23.9%; Table 1). Almost half of the individuals in this group ($n = 42,391$, 46.5%) were supported by care package 3 (24.5%) or care package 6 (22.0%) and thus required “medium” to “intensive” support in daily living, had medium care needs and were “limited” to “very limited” in their independence (Table 2). The complete overview of distribution across care packages for residential care is presented in Table 2.

Non-residential care

The non-residential care group consisted of 27,007 individuals with ID (46.7% male), with an average age of 40.4 years ($SD = 15.0$). The largest age group was the 25–34 years group (22.8%; Table 1). The majority of individuals in this group ($n = 20,955$, 77.6%) self-arranged their supportive care without further specification in the CCA database. Among those whose care utilisation was specified, 2149 individuals (8.0%) received outpatient treatment and care, 959 individuals (3.6%) received generic, not ID-specific care, and the remaining 2944 individuals (10.9%) received care for another primary reason other than ID (e.g., for a physical disability or mental health). Having another reason to call upon the CCA besides an ID was common in this subgroup. In the group of individuals with ID who had more than one underlying reason for using care ($n = 14,100$, 52.2%), the ID was the primary reason for 8758 individuals, and for 5342 individuals, the ID was a secondary reason. Most prevalent conditions besides an ID were a psychiatric condition ($n = 7433$, 27.5%) or a somatic condition ($n = 3494$, 12.9%). Further characteristics of this group are shown in Table 3.

Mild-ID

The Mild-ID group consisted of 69,078 individuals (63.4% male), with an average age of 38.4 years ($SD = 14.6$). The largest age group was the 18–24 years group (25.9%), and 1828 individuals (2.7%) were aged ≥ 65 years (Table 1). Most individuals were supported by a single service only, being related to work in sheltered workplaces ($n = 49,861$, 72.2%), receipt of disability benefits ($n = 11,631$, 16.8%) or chronic care ($n = 3033$, 4.4%). The remaining 4553 individuals (6.6%) were supported through a combination of two or more of these services (Table 4).

Discussion

By linking three national databases, this is the first study to have identified individuals with ID in administrative population data in

Table 1
Demographics of the general adult Dutch population (GenPop) and the ID subgroups^a.

Demographics	GenPop, N = 12,677,768 (98.5%)		ID groups combined N = 187,152 (1.45%)					
			Residential care, N = 91,064 (0.7%)		Non-residential care, N = 27,007 (0.2%)		Mild-ID, N = 69,078 (0.5%)	
	N	%	N	%	N	%	N	%
Sex								
Male	6,196,789	48.9	50,983	56.0	12,624	46.7	43,763	63.4
Female	6,480,979	51.1	40,081	44.0	14,383	53.3	25,315	36.6
Age, M (SD)	48.3 (17.8)		40.3 (16.4)		40.4 (15.0)		38.4 (14.6)	
18–24 years	1,362,047	10.7	21,727	23.9	4727	17.5	17,892	25.9
25–34 years	1,931,948	15.2	17,898	19.7	6160	22.8	12,557	18.2
35–44 years	2,225,395	17.6	14,626	16.1	5739	21.3	12,149	17.6
45–54 years	2,457,868	19.4	16,584	18.2	5421	20.1	15,104	21.9
55–64 years	2,104,631	16.6	12,519	13.7	3143	11.6	9478	13.7
65–74 years	1,551,963	12.2	5640	6.2	1260	4.7	1870	2.7
≥75 years	1,043,916	8.2	2070	2.3	560	2.1	28	0.04

ID, intellectual disabilities.

^a Total population size to base prevalence calculation on was n = 12,864,827.

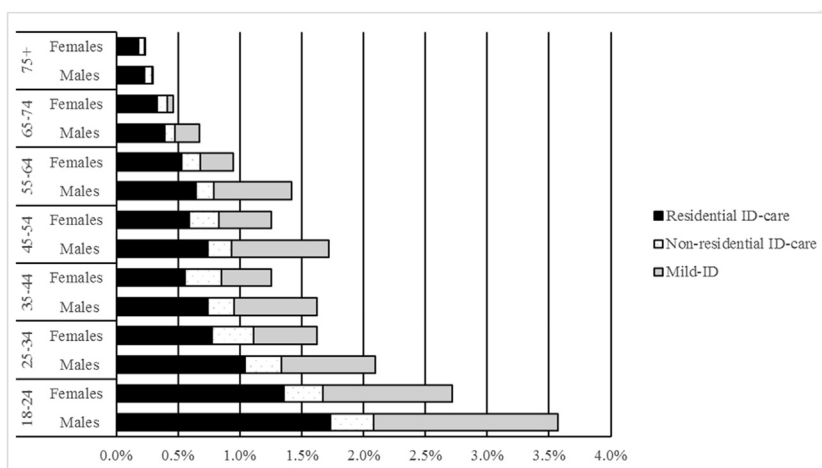


Fig. 2. Prevalence estimates per ID severity group, by age and sex. ID, intellectual disabilities.

The Netherlands and to consequently provide an estimate for the ID prevalence in the Dutch adult population. Combining administrative data on chronic care and welfare benefits gave an ID prevalence estimate of 1.45%. Based on the level of support needs, the ID population could be classified as residential care, non-residential

care or Mild-ID, with a prevalence of 0.7%, 0.2% and 0.5%, respectively.

Good quality data should be the basis for decision-making in the policy and practice of public health. However, access to accurate data has been lacking in the ID field, especially at the population

Table 2
Distribution of individuals with ID across residential care packages^b.

Package	Level of required guidance in daily living and activities (0–4) ^a	Level of required care (0–4)	Level of Independence (0–4) ^a	Total, n (%)
1	1-Some	0-None	1-Fairly independent	734 (0.8)
2	2-Medium	0-None	2-Some limitations	4639 (5.1)
3	2-Medium	2-Medium	2-Some limitations	22,350 (24.5)
4	2-Medium	3-Intensive	3-Very limited	11,949 (13.1)
5	3-Intensive	3-Intensive	3-Very limited	10,733 (11.8)
6	3-Intensive	3-Medium with behaviour therapy	3-Very limited	20,041 (22.0)
7	4-Very intense	3-Medium with behaviour therapy	3-Very limited	12,867 (14.1)
8	2-Medium	4-Complete care and nursing	4-Completely dependent	7751 (8.5)
				91,064

ID, intellectual disabilities.

Source: User guide Intellectual disabilities—Information per care package, National health care institute, and Care profiles, Care Needs Assessment centre (CIZ), <https://www.ciz.nl/images/pdf/beleidsregels/Zorgprofielen.pdf>.

^a Categories 0-No guidance required and 0-Completely independent do not occur.

^b Package refers to the pre-arranged care packages available to individuals in this group.

Table 3
Distribution of individuals with ID across types of non-residential care.

Description of care	ID primary diagnosis	ID secondary diagnosis	Total, n (%)
Self-arranged without residency, not specified	19,217	1738	20,955 (77.6)
Functional treatment without admission or residency	2179	7	2186 (8.1)
Sensory disability care	111	989	1100 (4.1)
Mental health care	13	991	1004 (3.7)
General care and nursing (not ID-specific)	110	849	959 (3.5)
Physical disability care	35	768	803 (3.0)
	21,665	5342 ^a	27,007 (100)

ID, intellectual disabilities.

^a Distribution of 5342 primary diagnoses other than ID: psychiatric 2238 (41.9%), sensory disability 1061 (19.9%), physical disability 945 (17.7%), somatic disease 783 (14.7%), psychogeriatric 315 (5.9%).

Table 4
Distribution of people with Mild-ID support needs.

Eligibility	Total, n (%)
<i>Single service use:</i>	
Sheltered workplace only	49,861 (72.2)
Disability benefit only	11,631 (16.8)
Chronic care only	3033 (4.4)
<i>Combined use of services:</i>	
Sheltered workplace and disability benefits	2554 (3.7)
Sheltered workplace and chronic care	238 (0.3)
Disability benefit and chronic care	1643 (2.4)
User of all three services	118 (0.2)
	69,078 (100)

Distribution presented as observed after combining data from CCA (Chronic Care Act) and social benefits databases.
ID, intellectual disabilities.

level because of the difficulty in identifying individuals with ID consistently across different data sets.^{20–22} The current method for data linkage and identification of ID groups can contribute to better retrieval of relevant information on the ID population. For example, this linkage method can provide a more accurate insight into the population size requiring ID-related public health services, keep track of developments over time and help to monitor effectiveness of interventions targeted at the ID population level. For specific future research investigations, the current method generates the largest possible cohort of Dutch individuals with ID.²³

This study estimated a 1.45% ID prevalence in the Dutch adult population, which is in line with the literature. Previous studies mostly based their ID prevalence estimates on ID diagnoses, which suggests that the true ID prevalence might be closer to the upper limit (or even higher) rather than the lower limit of the generally reported prevalence estimates of between 1% and 1.5%.^{14,24,25} In particular, this study found that in the younger age groups, ID prevalence rates were above 2.0% based on care use alone and above 3.5% when the Mild-ID group was included. In terms of the Mild-ID group, this study included individuals whose diagnosis is likely to be based on functional limitations or IQ scores only, rather than the conventional case definitions for ID, which also include limitations in adaptive functioning.^{16,17} If the results were limited to individuals with ID receiving residential or non-residential care, the overall ID prevalence estimate amounts to 0.93%, which is slightly below the generally reported prevalence.¹⁴

While this investigation has successfully identified 67,078 individuals with a Mild-ID, other studies have previously suggested that, based on the normal distribution of IQ scores within a population, the total group of people with a Mild-ID in The Netherlands might be as large as 1.1 million people.²⁶ It is important to note that the underidentification of people with mild ID is a common problem of studies using administrative data.^{11,22,24} Individuals with mild ID may not all rely on national systems for daily care and

support, in contrast to those with more severe ID. Instead, supportive care to people with mild ID is more frequently organised by local and municipal programmes, of which the information is not included in national databases. In this study, we identified this group of individuals primarily through work- and income-related support systems; therefore, it could be seen as a sample of people with a mild ID and (some) capacity to do labour, albeit in a protective setting.

A limitation of using this type of administrative data is the absence of information about actual ID diagnoses. Although having an ID diagnosis is required to gain access to any of the services of which the data were used in this study, information about the diagnosis itself was not registered in any of the databases. For the administrative functioning of these databases, or the supportive systems themselves, detailed information on diagnoses is also not required; however, individuals with ID who are without a formally established diagnosis would not only be missing in the databases but might also lack access to services they require. Furthermore, the information available in this study showed which services individuals with ID were registered for, but not if these services were all used to the full extent as indicated. Information about diagnostic subgroups, for example, in DSM-V or ICD-10 classifications, would allow to further characterise subgroups, to identify any underrepresented groups and allow for international comparisons in a standardised manner.

A major strength of this study is the successful unique identification of people with ID at the national level. Although data were anonymised, the use of the unique identifier (RIN number) enabled the study to count users of multiple services as unique individuals across data sets. Moreover, the RIN number allows future linkage to a range of other data sets on health and well-being that do not necessarily require information about ID to be informative about individuals with ID. Examples can be found in our work on mortality, cancer and diabetes, which all rely on the methodology described in this study.^{23,27,28} Both the national coverage and the RIN number therefore allow structural monitoring of trends in health and health care among people with ID and potentially also other vulnerable groups within Dutch supportive systems.²⁹

Conclusions

This study successfully identified individuals with ID among users of national supportive services. The estimated ID prevalence in this study aligns with international estimates and shows a decline with increasing age. Databases from national supportive services therefore appear to be a useful resource to identify individuals with ID at the population level. As the current method is reproducible and relies on standard collected data, it provides opportunities for consistent monitoring of the Dutch population with ID in administrative data.

Author statements

Ethical approval

The study protocol for this exploratory study was reviewed by the Radboud University Medical Center institutional Ethics Committee who passed a positive judgment and waived the need for formal ethical assessment (2017–3921).

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Competing interests

Authors declare to have no conflicts of interest.

Data availability

Aggregated data from the databases used in this study are publicly available on a dedicated website of Statistics Netherlands (<http://statline.cbs.nl>). The non-public microdata used to link databases are, under certain conditions, accessible for statistical and scientific research (fees apply). Procedures can be found at www.cbs.nl, for further information: microdata@cbs.nl.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.04.002>.

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