

# National register for people who are deaf and hard-of-hearing (DHH), or have a developmental language disorder (TOS): **towards accessible data infrastructure**

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**No single data source tells us who they are, how many there are, or what their outcomes look like over time**

**“When asked how many DHH people worked in sheltered employment, the government could not provide the information because disability type was not registered.”**

— Dutch Parliament, 2013

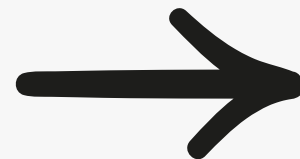
**“How many DHH students in total participate in regular education is not known, because this group is not registered as such.”**

– Hogeboom & Scholten, 2022

# Data exists, but it's fragmented



Statistics  
Netherlands



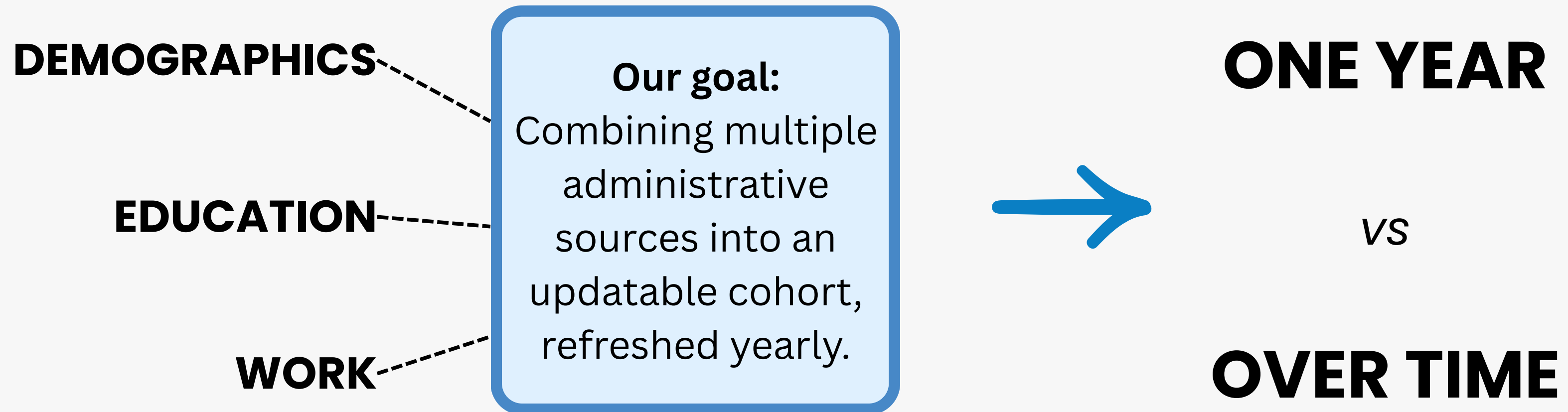
**The reality:**

"There is no  
disaggregated  
data"

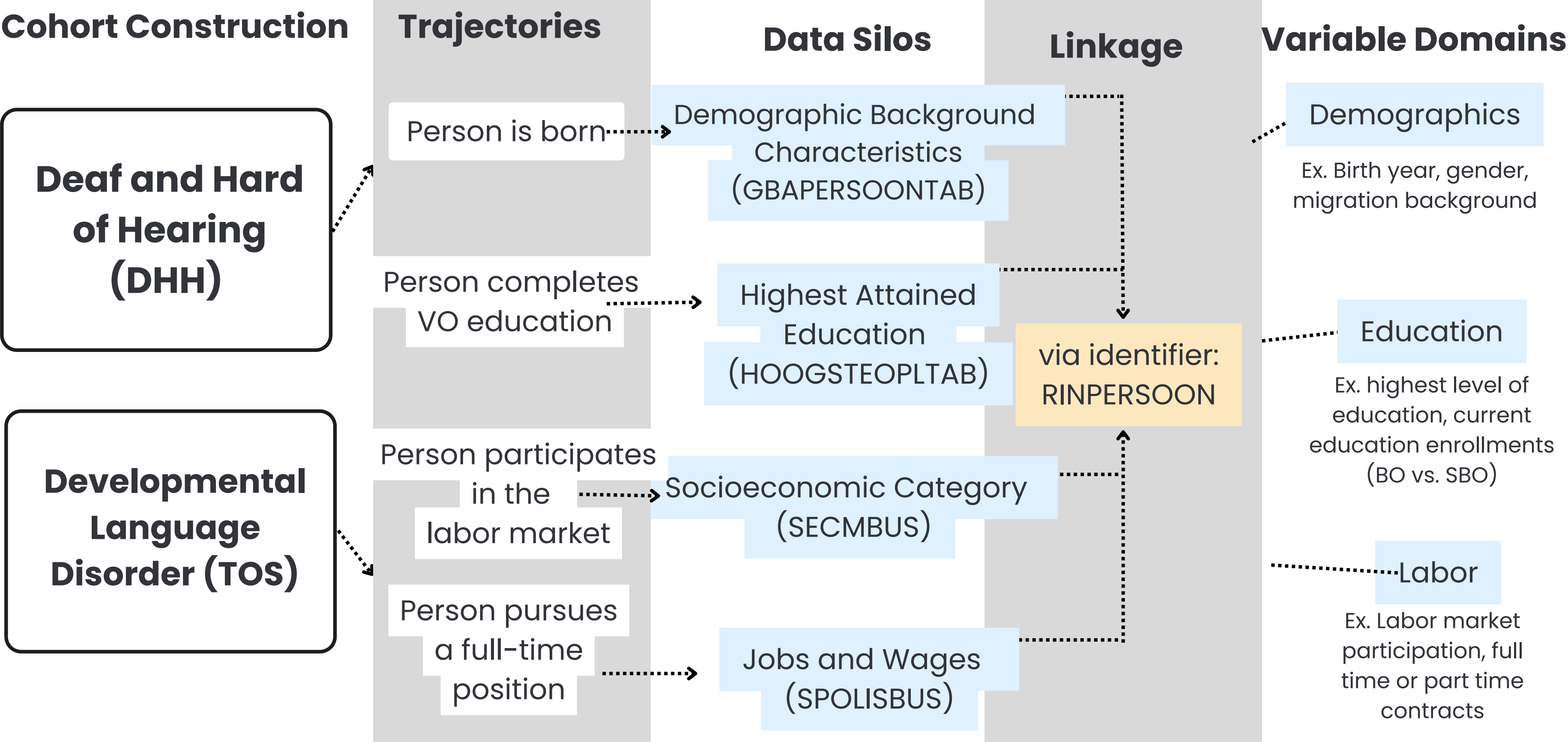
Internationally, weak population-level data is well documented as a barrier to designing inclusive policy, monitoring inequities, and evaluating whether services actually work (UN, 2016)

# One proposed fix to this problem is a register

A person level dataset that defines core target populations



# Data Warehouse (inside CBS remote access)



# Why is this more complex than it sounds?

*so we combine sources carefully and document every choice*

## **Different sources**

Each records a different group of people

## **Different purposes**

Built for billing and services, not research

## **Different definitions**

A diagnosis isn't the same as "DHH"

## **Different years**

Coverage and coding change over time

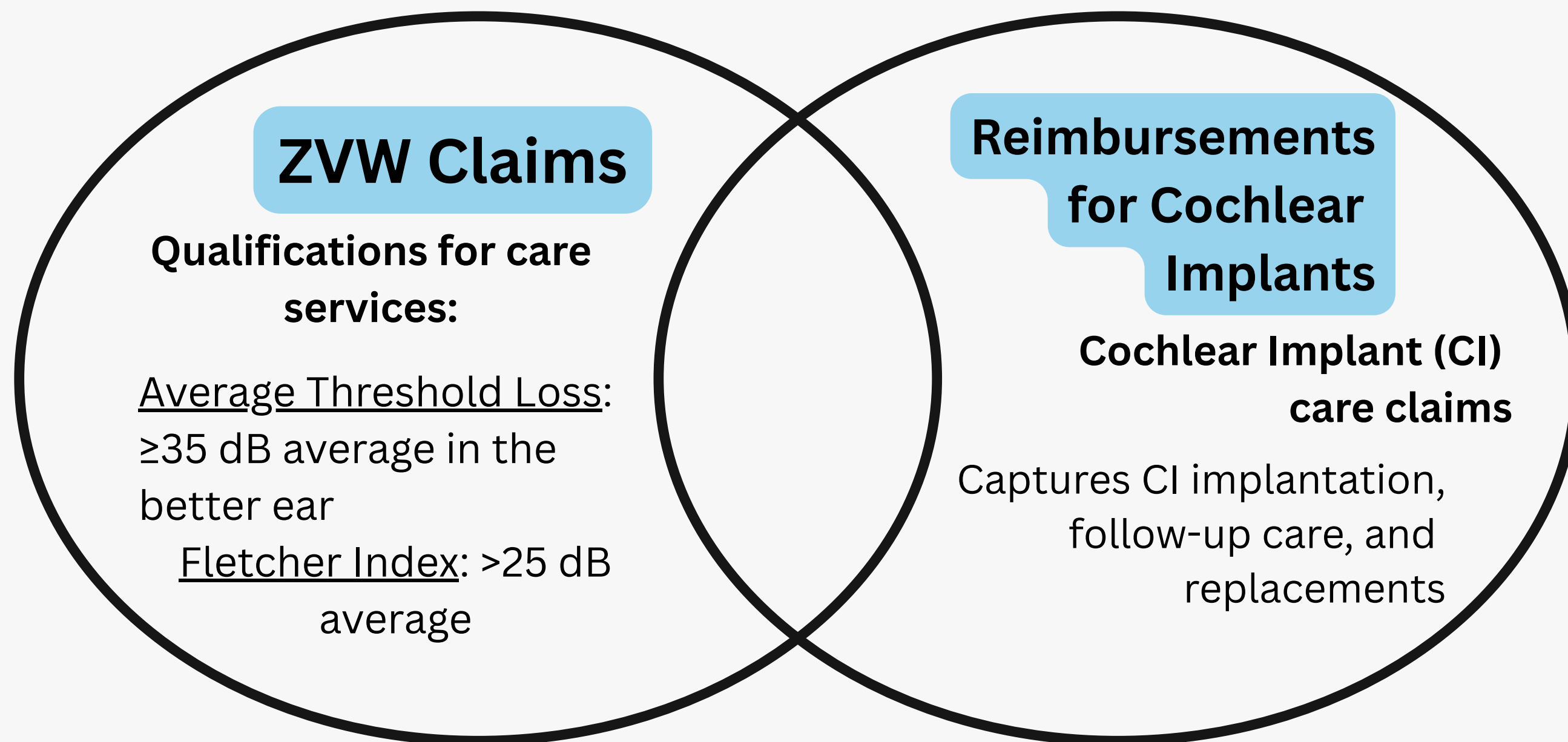
# Method used to construct TOS indicator

## ZVW Claims

### **Sensory disability insurance claims for care services:**

- Persistent, severe difficulties in the development of language that are disproportionate to the individual's overall developmental level

# Method used to construct DHH indicators

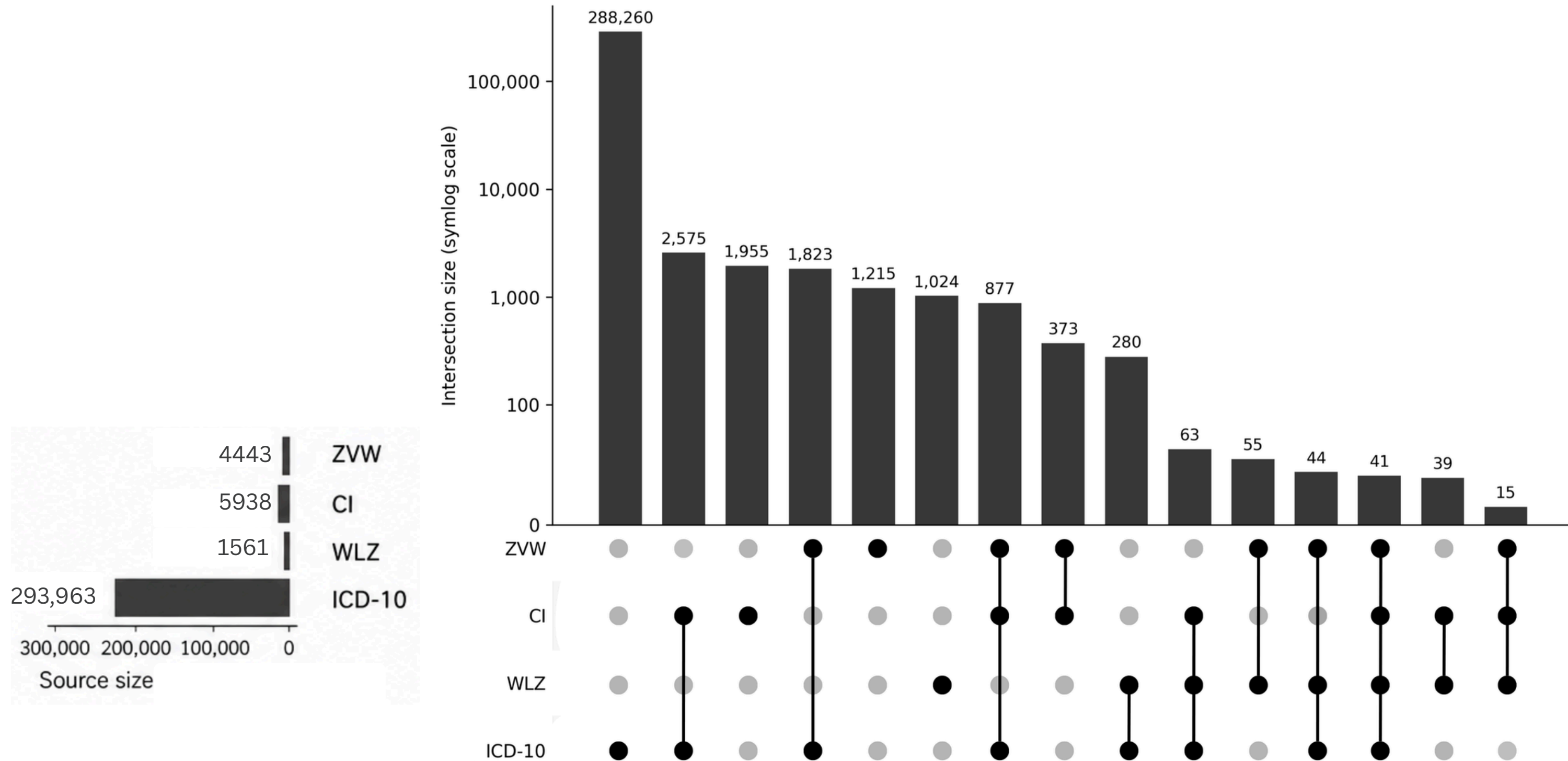


Additional sources we are exploring:

- **INDICWLZ:**  
Auditory codes
- **MSZSUBTRAJECTEN**
  - ICD-10 codes categorized as “DHH”
  - Hearing aid subtrajectories

# Intersection between DHH identification sources

ZVW, CI, WLZ auditory profile, and ICD-10 • 2016-2017 • N = 298,639



## Source

- ZVW = healthcare claims (Zvw)
- CI = cochlear implant
- WLZ = long-term care (Wlz) – auditory profile
- ICD-10 = specialist data (MSZ) – hearing diagnosis

## Combination matrix

- Source included in combination
- Source not included
- Multiple sources in combination

# One code, three definitions of “DHH”

ICD-10:

## H90-91

Deaf and hard of hearing people share these codes, with a variety of associated diagnoses

Which codes would you prefer to use when building a register?

**A.**

Broad

*anyone with a hearing-related diagnosis*

VS

**B.**

Repeated contact

*a hearing-related diagnosis recorded more than once*

VS

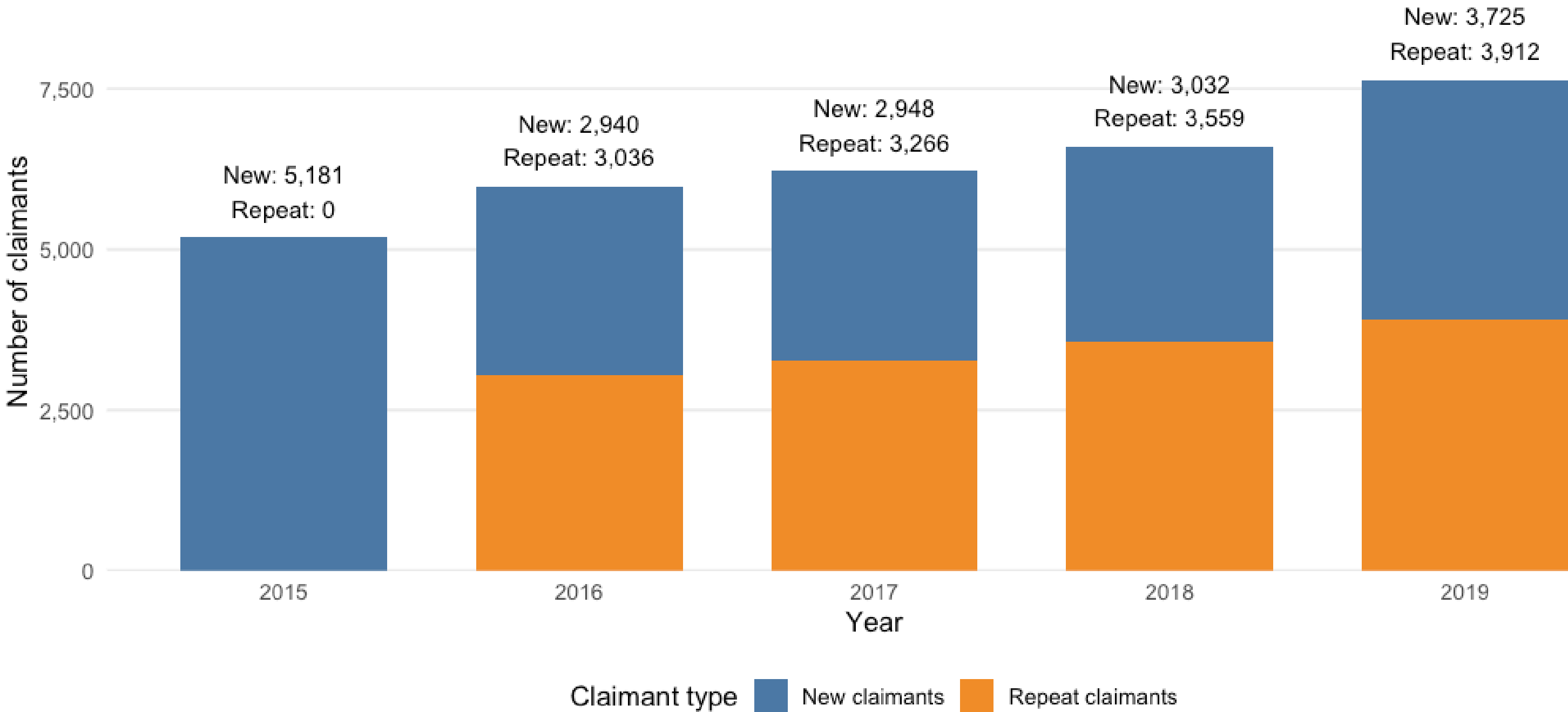
**C.**

Corroborated

*a diagnosis plus a second source (ZVW)*

# TOS Claimants by Year

New and repeat TOS claimants, 2015–2019



Gender

**72% | 28%**

Male      Female

Migration Background

**5% | 34% | 61%**

1st      2nd      Nether-lands

Age Mean (yrs) = **13**  
Range (yrs) = **0-26**



# Potential Dashboard:

## DHH & TOS

Register

Overview

Labor Market

Population

Education

Register Growth

Methodology

Downloads

## NATIONAL REGISTER - DHH & TOS

Labor market outcomes and population characteristics | CBS microdata, 2015-2019

DHH

TOS

2015-2019

Group

Year

People in register (2019)

11,749

17,686

DHH

TOS

New entrants (2019)

1,195

3,710

DHH

TOS

Mean age (SD)

41.7 (27.9)

7.0 (3.8)

DHH

TOS

Labor participation, Dec 2019 (15-65)

~43%

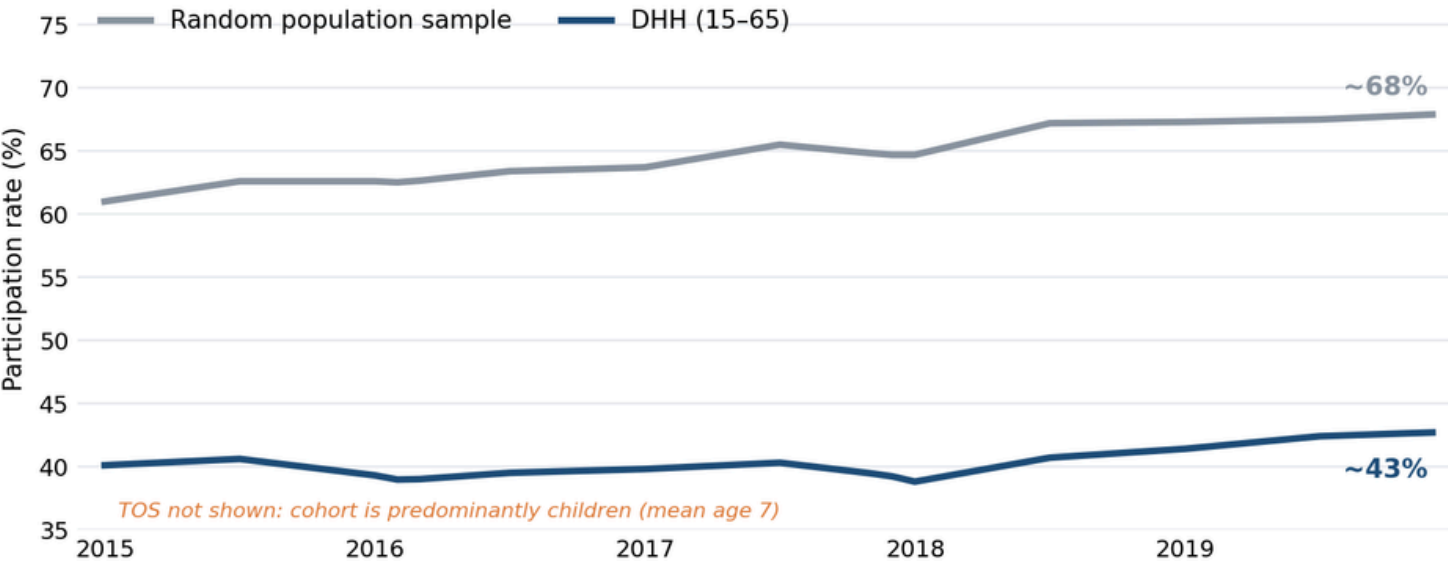
n/a

DHH

TOS (mean age 7)

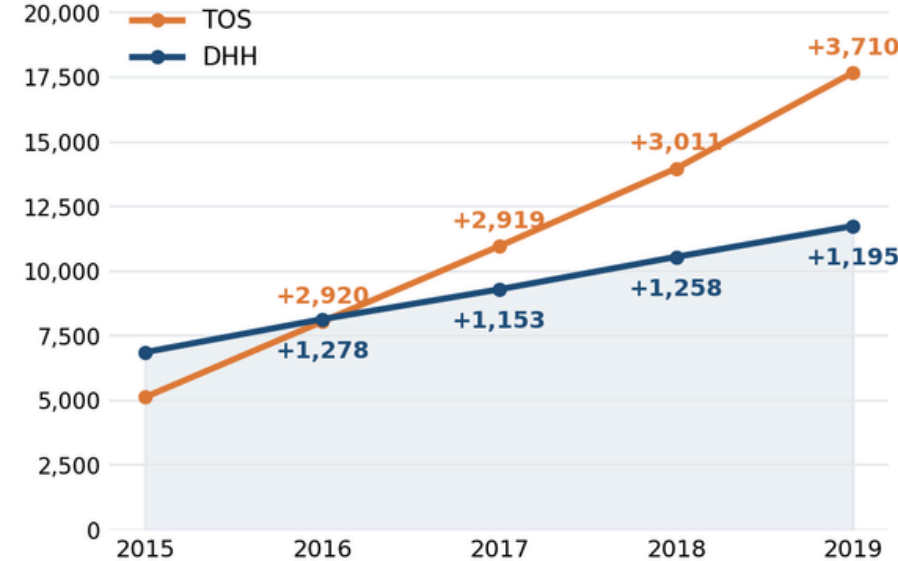
### Monthly labor market participation rate

DHH claimants (ages 15-65) vs. random population sample, 2015-2019

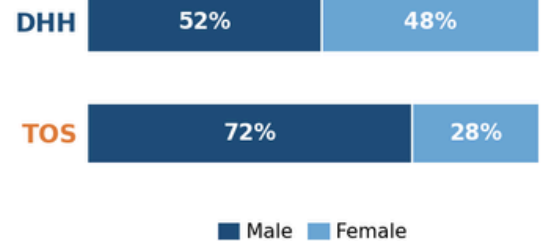


### People in register

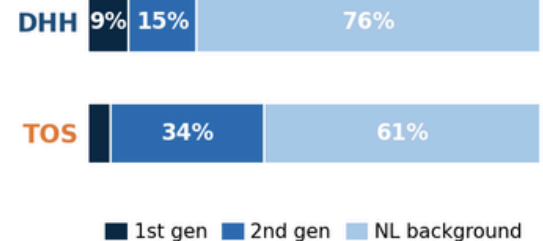
Total per year (labels: new entrants)



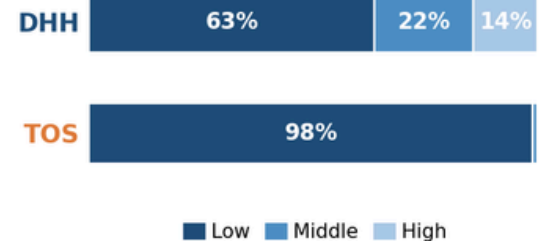
### Gender



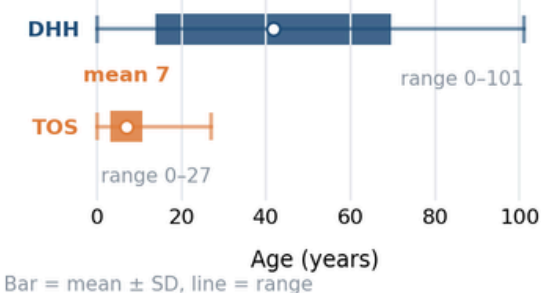
### Migration background



### Highest education



### Age



Source: CBS microdata, national DHH & TOS register, 2015-2019. Illustrative dashboard mockup.

# Next Steps

1. Which sources count as DHH and TOS by default?
2. **Create a sub-cohort of hearing aid users:** care trajectories or reimbursements?
3. **Gather feedback from Deelkracht researchers and people with lived experience:** which outcomes and breakdowns matter most for a national register?
4. Hopefully build out the dashboard next year

# A lasting, public resource

## **What variables interest you?**

Imagine being able to discover  
real-time data based on your  
interests, through a customizable  
dashboard!

# THANK YOU

## Questions or feedback?

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# Citations

## Slide 2:

Tweede Kamer der Staten-Generaal. (2013). Antwoord op vragen van de leden Bergkamp en Van Laar over de participatie van doven en slechthorenden binnen de samenleving. Aanhangsel Handelingen II 2012/13, no. 2990 (document no. ah-tk-20122013-2990).

Hogeboom, L., Scholten, C., & DSP-groep. (2022). Recht op onderwijs voor dove en slechthorende leerlingen. In DSP-groep RAPPORT [Report]. DSP-groep. [https://www.dsp-groep.nl/wp-content/uploads/2025/04/Rapport-Recht-op-onderwijs-voor-dove-en-sh-leerlingen\\_DSP-groep\\_2022-1.pdf](https://www.dsp-groep.nl/wp-content/uploads/2025/04/Rapport-Recht-op-onderwijs-voor-dove-en-sh-leerlingen_DSP-groep_2022-1.pdf)

## Slide 3:

United Nations Economic and Social Council. (2016). Mainstreaming disability in the implementation of the 2030 Agenda for Sustainable Development: Report of the Secretary-General (E/CN.5/2017/4). United Nations.