

# RECOGNISING DISABILITIES AND BARRIERS!

Key findings from a Rare Barometer survey  
on the impact of living with a rare disease in Australia

February 2025



10 July  
8 Sept. 2024



78  
respondents  
in Australia



54  
rare diseases  
represented

## 1 MOST PEOPLE WITH RARE DISEASES IN AUSTRALIA LIVE WITH DISABILITIES



9/10

people with rare diseases  
in Australia  
live with disabilities



*Washington Group Short Set on Functioning (WG-SS): 92% of the participants had 'some difficulties', 'a lot of difficulties' or 'could not at all' see, hear, walk, remember/concentrate, selfcare (dressing or washing over) or communicate; Global Activity Limitation Index (GALI): 87% of the participants were limited or severely limited in performing activities that people usually do because of a health problem during the last 6 or more months; self-identification: 90% of the participants considered themselves as a person with a visible disability, an invisible disability or both. All participants (n=78).*

## 2 A MAJORITY LIVE WITH DIVERSE AND COMPLEX DISABILITIES

86% had difficulties with  
at least 2 activities :



Sight



Hearing



Walking or  
climbing  
stairs



Remembering  
or concentrating



Selfcare



Communication



*Percentage of people with rare diseases who had 'some difficulties', 'a lot of difficulties' or 'could not do at all' in at least 2 domains of the WGSS - All participants (n=78); The six domains of the Washington Group Short Set on Functioning (WGSS).*

### 3 PEOPLE WITH RARE DISEASES IN AUSTRALIA DO NOT RECEIVE ADEQUATE SUPPORT...



51%

found it difficult or very difficult to obtain publicly funded support such as attendant care support, home support, financial support, assistive technology, mobility aids or other support.



'How difficult do you find it to obtain State support such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.?' - All participants (n=78).

### 4 ...AND THEY DO NOT TAKE PART IN SOCIETY ON AN EQUAL BASIS WITH OTHERS

Most people with rare diseases in Australia experienced discrimination:



72%

experienced discrimination related to the rare disease or disability in healthcare, in employment, in education, in housing, in public accommodations or in other places.



Percentage of participants who answered 'In healthcare', 'In education', 'In employment', 'In housing', 'In other public accommodations (hotel, restaurants, transport, museums, etc.)' or 'other' to 'Have you ever experienced discrimination related to the rare disease or disability?' - All participants (n=78).

Unemployment of people with rare diseases in Australia is higher than in the European Union:



35%

of people with rare diseases in Australia are unemployed

Comparison: the unemployment rate in the general population of the European Union was 6.1% in 2023<sup>1</sup>.



Percentage of participants aged 16-64 who answered 'Unemployed' or 'Cannot work because of a disease' to 'What is your current situation?' (n=52).

More information: [eurordis.org/voices](https://eurordis.org/voices) or [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)

Full report in English: [tiny.cc/survey/RB\\_DailyLife](https://tiny.cc/survey/RB_DailyLife)

**THANK YOU** to all the people with rare diseases and family members who participated in the survey, and to Rare Barometer partners!

1. Unemployment rates by sex, age and citizenship, Eurostat ([https://ec.europa.eu/eurostat/databrowser/view/lfsa\\_urgan\\_custom\\_15225487/default/table?lang=en](https://ec.europa.eu/eurostat/databrowser/view/lfsa_urgan_custom_15225487/default/table?lang=en)), consulted February 3rd 2025.