Huntington's Australia

HAVE YOUR SAY IN 2024

COMPLETE SURVEY RESULTS

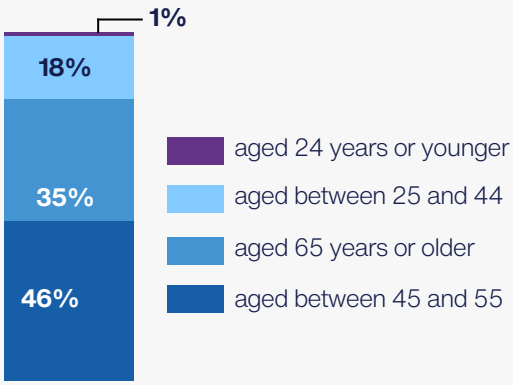
In June 2024, Huntington's Australia conducted the "Have Your Say" survey, which was distributed via email and social media to members, clients, donors, stakeholders, and supporters.



Out of 2,549 emails sent, **188 responses were received**, resulting in a 7% response rate. While this is below the typical 10-30% range, the outcome is considered reasonable due to HA's audience demographics and the recent merger.

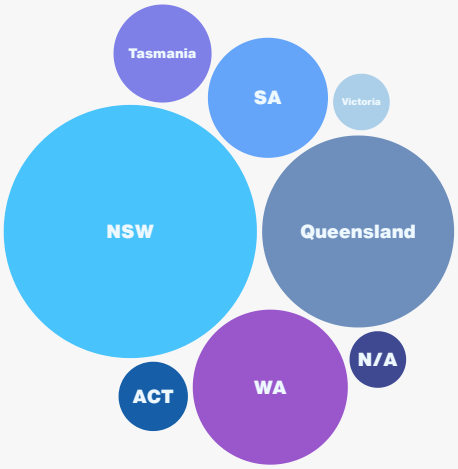
PROFILE OF RESPONDENTS

Age



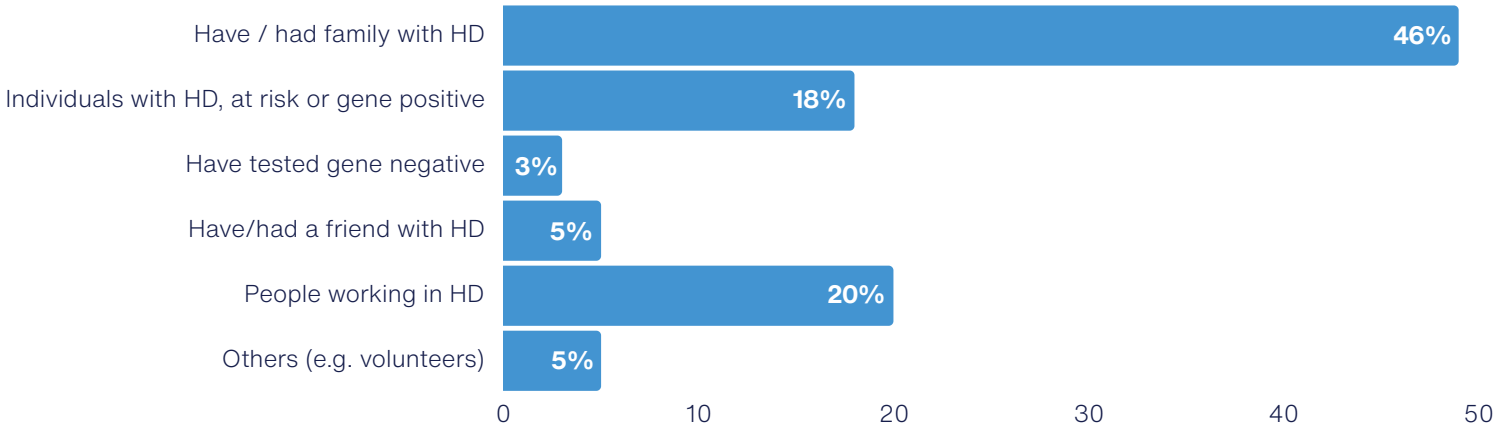
Location

The percentage of respondents from each state and territory are as follows:



- **Queensland** 23%
- **NSW** 40%
- **SA** 9%
- **Tasmania** 6%
- **WA** 15%
- **ACT** 3%
- **Victoria** 2%
- **N/A** *(Respondents skipped the question):* 2%

Connection to HD



Purpose of Huntington's Australia

1. Raise awareness of HD (through education, advocacy and lobbying)
2. Support the HD community (people with HD, carers and families)
3. Provide information on research, treatments and better care

Importance of our services

Family support

One on one support

Welfare support
(help with Centrelink, Medicare, NDIS, Aged Care packages)

Level of Satisfication

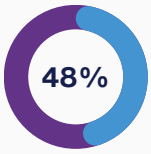
We asked individuals to rate their level of satisfaction with our services. Below are a few responses:

28.89% of respondents reported being **'Very Satisfied'** with **One-on-One support**

20.33% of respondents reported being **' Neutral'** with **Education and Training for Providers**

3.30% of respondents reported being **'Very Dissastisfied'** with **Communication Updates (social media, website)**

Additional comments about a specific service



Individuals gave additional comments about a specific service.

Positive comments were made about staff and how knowledgeable and skilled they are; the services we provide through NDIS and how much assistance we provide; providing support groups and counselling/guidance; having good comms (newsletters and social media updates).

Neutral comments were made about not yet needing the services, or not using any of our services but happy to support; wanting more support for teenage/young adult ages; needing to have more events and create more awareness.

Negative comments were made about running groups with unqualified leads; having no services outside capital cities; the constant changing and shifting of messages; delay in having support groups after COVID is disappointing.

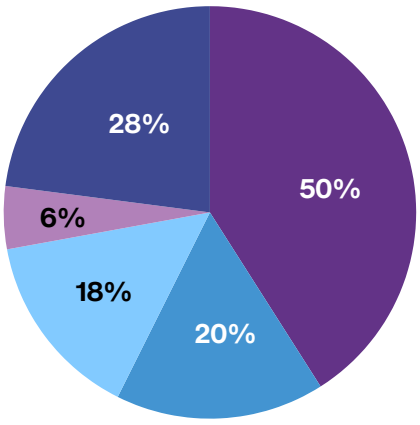
NDIS services of interest

We asked individuals to tell us which NDIS services would be of interest or applicable to them.



Our Strengths

This was an open-ended question in which 122 people responded and 66 people skipped this question. Below is a summary of the comments made.



- Support and care (Professionalism, organisational skills, knowledge, support groups)
- Awareness and advocacy (Social media, newsletters and comms, events)
- NDIS
- Training and education (Training for providers and carers
- Unsure or too early to tell

New services or programs you would like to see

Social work support/counselling

Education
- Intro and early signs
- Health professionals
- Family member/carers

Awareness Events & Conferences

Regional support

Research updates

Phone support/ How to guides

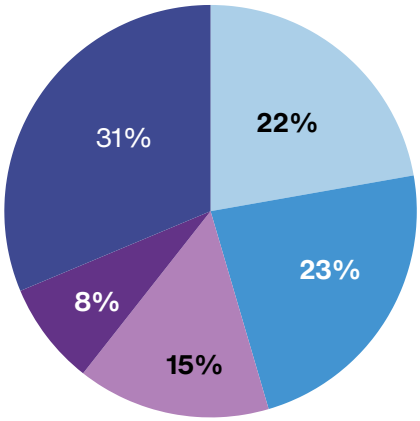
Youth support

Social activities

Financial support

Areas for Improvement

This was an open-ended question in which 99 people responded and 89 people skipped this question.
Below is a summary of the comments made.



- Awareness and advocacy (Advertising, funding, fundraising outside HD community)
- Support and care (Professional support groups, follow up with families, focus on people, training and education)
- New activities (Support groups at night/weekend, camps or lunch groups, regional support groups)
- Clear communication (Consistent messaging, volunteer recognition)
- Unsure or too early to tell

Huntington's Australia

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