

# Understanding TSC in Australia

## A family survey by Tuberous Sclerosis Australia

### Goals

1. To find out more about people living with TSC in Australia.
2. Gather feedback on current activities of Tuberous Sclerosis Australia (TSA).
3. Understand areas of need that TSA may be able to address.
4. Provide a way for people living with TSC to build their feelings of ownership over TSA.
5. Identify those who are willing to contribute to the organisation through volunteering, sharing their story, or fundraising.

### Methods

Paper survey modelled on survey used by Tuberous Sclerosis Association (UK). Adapted to Australian data standards and desired length to maximise response. Ten pilot respondents to refine survey. Distributed via TSA online and printed publications during 2014. Movie ticket competition encouraged online responses.

### How do they use health services?

43% of respondents reported attending a TSC clinic. 85% mostly visited the same general practitioner. 51% of respondents were aware of the TSC guidelines for diagnosis, surveillance and treatment.

Professional managing TSC	Frequency (n)
Paediatric neurologist	27% (21)
Neurologist	19% (15)
General practitioner	17% (13)
Paediatrician	14% (11)
Nephrologist	3% (2)
General physician	1% (1)
Other*	19% (15)

\* included parent manager and more than one specialist managing TSC care

Table 2: Reported health professional managing TSC care

### What activities should TSA undertake?

Respondents were asked to rank possible activities for Tuberous Sclerosis Australia:

Activity	Ranked as #1	Mean rank
Provide information about TSC	21	4.54
Help connect TSC families to medical professionals	9	5.46
Provide advice about living with TSC	7	5.66
Educate professionals about TSC	6	5.8
Fund research	12	5.94
Raise awareness of TSC	5	6.43
Provide emotional support to people living with TSC	4	6.46
Lobby and campaign to improve health care for people affected by TSC	5	7.15
Practical (for example for advice on government benefits, services that may assist you live your life)	3	7.35
Host conferences for medical professionals and researchers	5	7.51
Advocate for individuals and families	5	7.79
Lobby and campaign to improve social services and benefits for people affected by TSC	0	7.9

Table 3: Priorities for TSA activities. Lower mean rank indicates higher priority

### More information

This was the first extensive survey conducted by TSA. Twelve recommendations have been made to the TSA management committee. These have informed the strategic plan that will guide TSA's activities. To view these, the full survey report, and the survey instrument, go to [tsa.org.au/survey](http://tsa.org.au/survey) For more information, please contact Clare Stuart [clare@tsa.org.au](mailto:clare@tsa.org.au)

### Who completed the survey?

88 respondents out of 400 TSC affected families in regular contact with TSA (22%) The geographic distribution reflected Australian population. Limited response from culturally and linguistically diverse populations. No respondents identified as Indigenous. Limited response from individuals with TSC (n=7, 8%); majority were parents of a child or adult with TSC

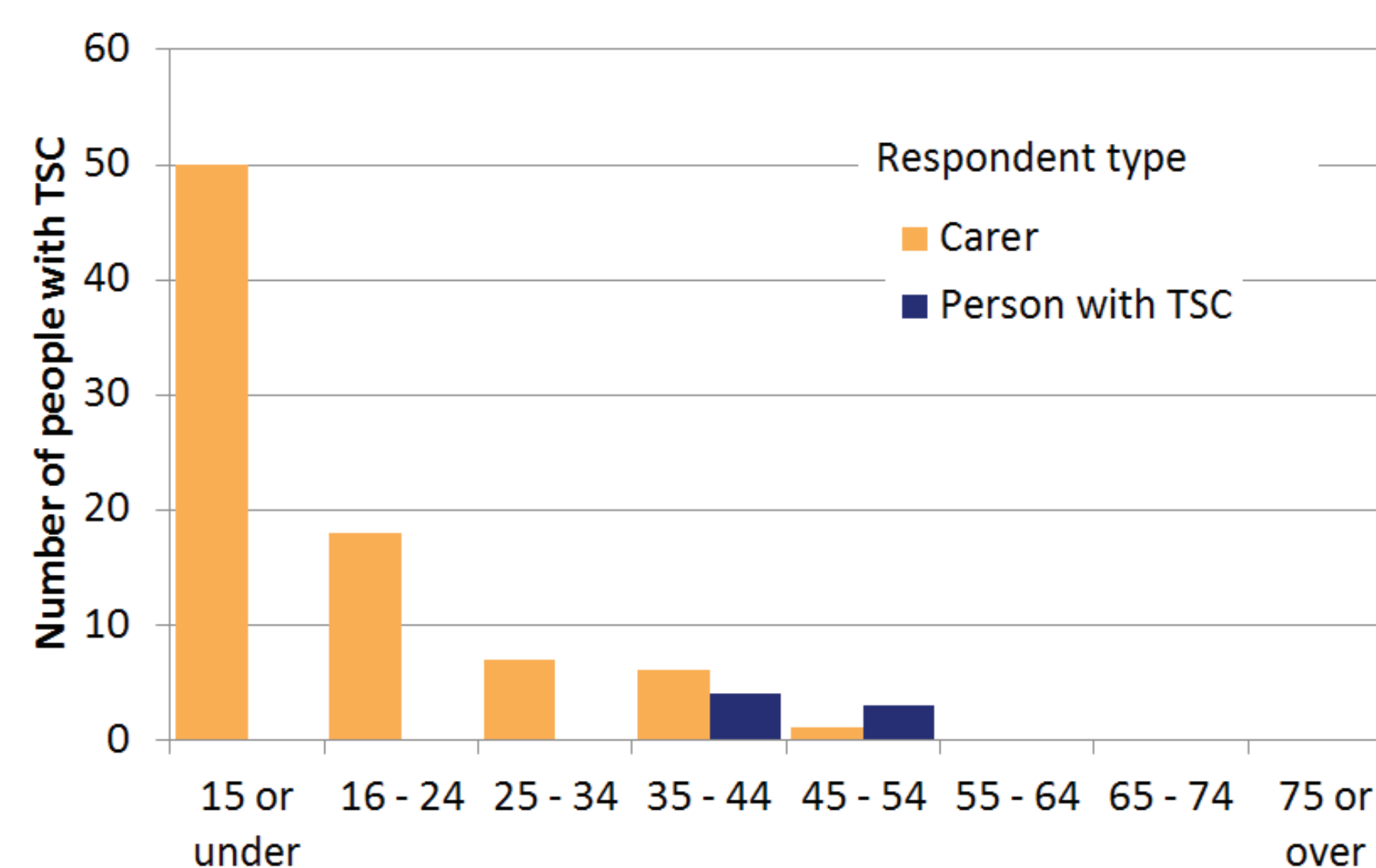


Figure 1: Age of people with TSC for whom the survey was filled out

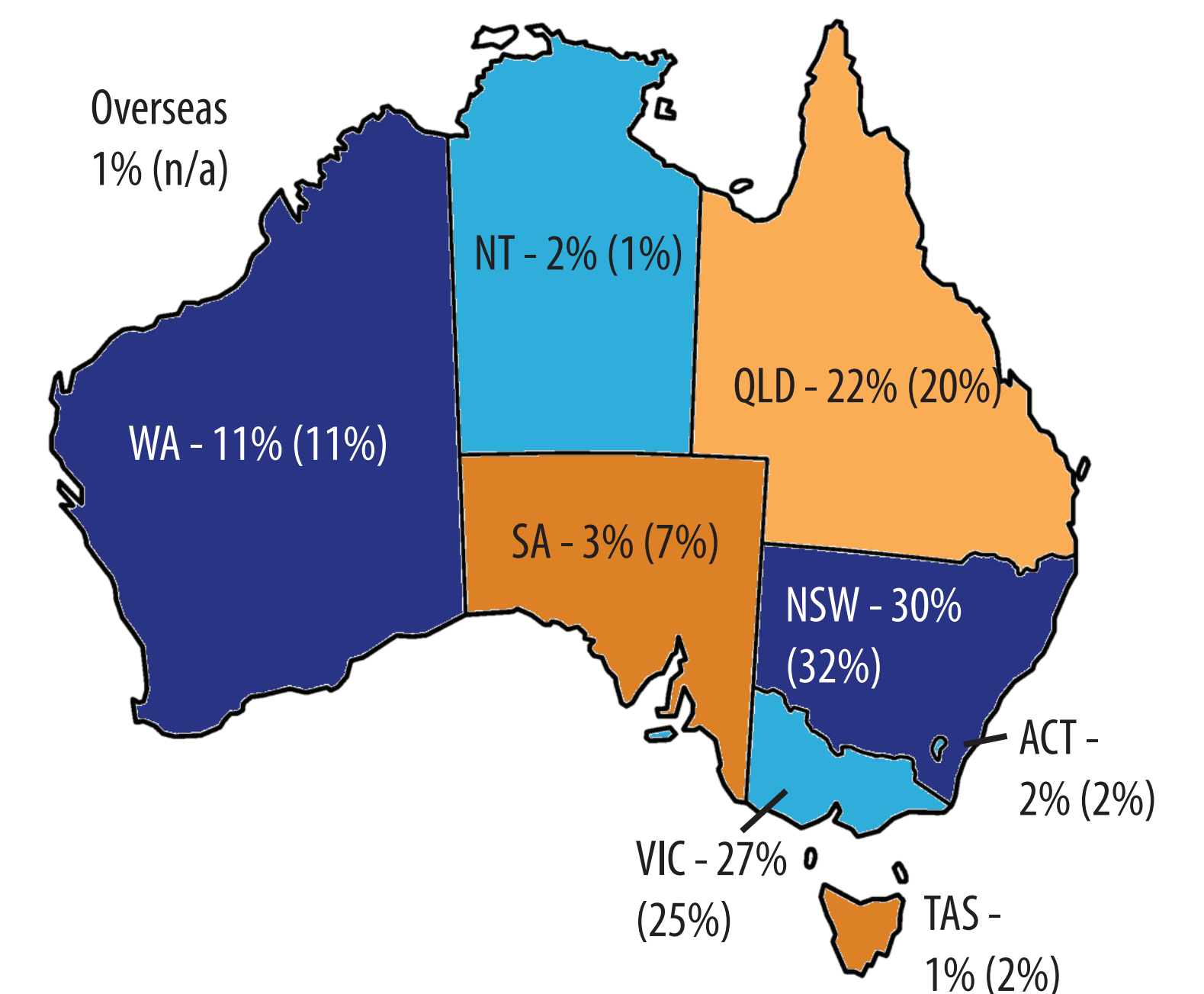


Figure 2: Distribution of respondents within Australia (proportion of Australian population)

### How does TSC affect them?

The respondents were provided with a list of conditions commonly associated with TSC. They were asked to report if these affected themselves or the person they cared for. Respondents were then asked to report on the impact that these conditions had on their lives

The survey also asked respondents to describe how TSC affects them. 65 out of 88 respondents (74%) provided an open text response.

Condition	Frequency (n)
Skin problems	88% (77)
Epilepsy	80% (70)
Learning difficulties	75% (66)
Kidney tumours or cysts	72% (63)
Intellectual disability	64% (56)
Challenging behaviour	58% (51)
Other (e.g. eyes, liver)	48% (42)
Autism	42% (37)
SEGA brain tumour	33% (29)
Mental health issues	25% (22)
Mobility problems	24% (21)
ADHD	16% (14)
Lung issues (e.g. LAM)	10% (9)

Table 1: Reported incidence of TSC related conditions

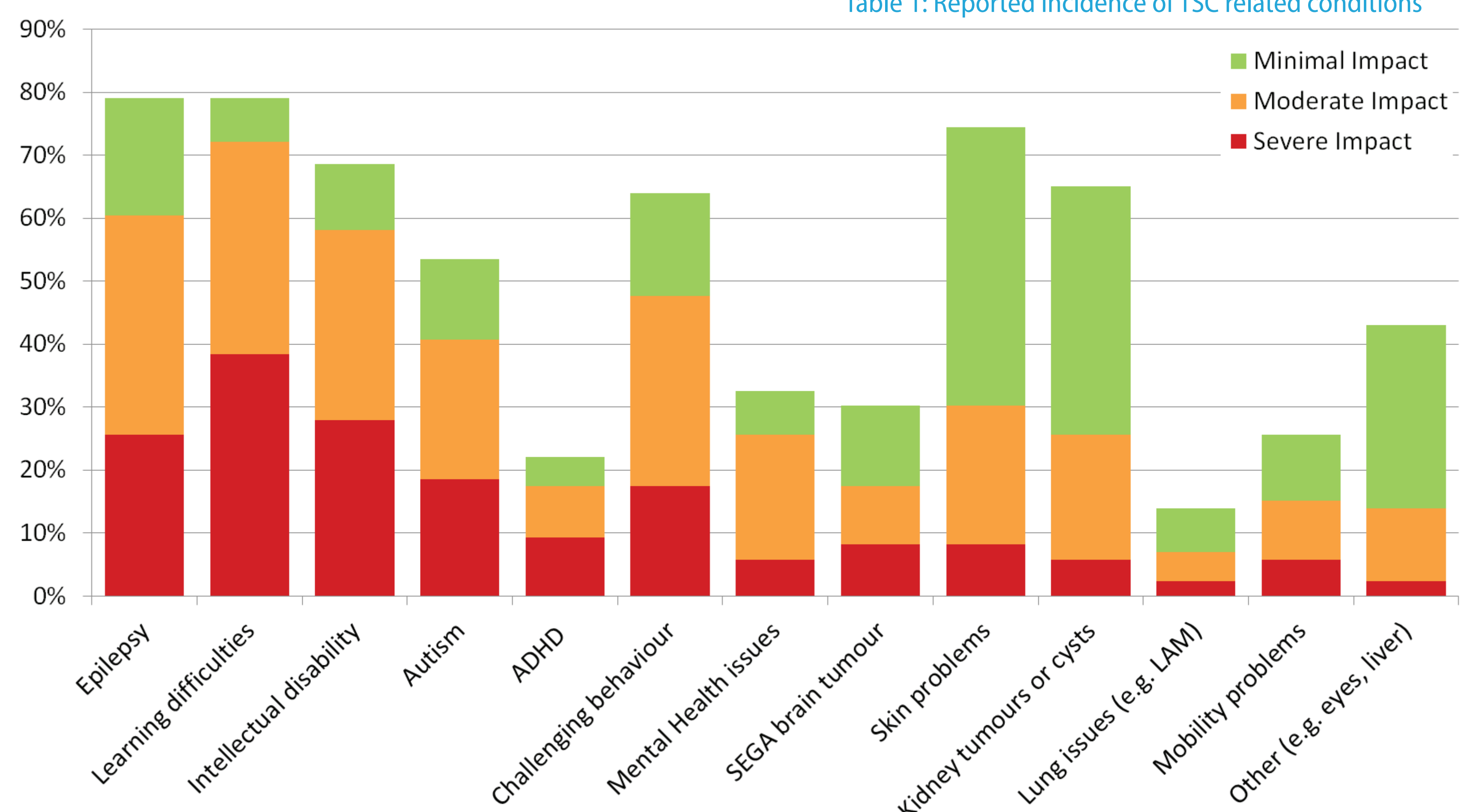


Figure 3: Reported impact of TSC related conditions on individual with TSC and their family

"My biggest concern is his social interactions, in the home, at work and with minimal friends. I worry about what the future holds and whether he will be ever able to independent. I worry that he will be lonely."

Parents of a teenager with TSC

"Although our son has been with a service provider we feel that we are always 'on call'. Our son has never completely accepted his second home. We do have holidays but with a great deal of stress because we always return to find there have been dramas and acting up."

Elderly parents of an adult with TSC



Tuberous Sclerosis Australia