

Interpreting data on  
Autism Spectrum Disorders  
from (a few)  
Australian Government sources

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# Sources of autism data

- Centrelink/FaHCSIA and Carer Allowance (child)
- FaHCSIA Helping Children with Autism (HCWA)
- Australian Bureau of Statistics (ABS)  
Survey of Disability, Ageing and Carers (SDAC)

*and more ...*

# Centrelink/FaHCSIA Carer Allowance (Child)

- caring for child 0 to 15 years (<16 years)
- diagnosed by (allied) health professional
- pays parent \$114 per fortnightly & health care card for the child, *not means tested*
- **population data:** includes *most* ... does not include everyone.
- Analysis below includes Autistic Disorder & Asperger's Disorder
  - this analysis omits Rett's Disorder, Childhood Degenerative Disorder (CDD)
  - data omits PDD-NOS
- Basis for AABASD's prevalence report 2007

# AABASD's prevalence report (2007)

- “... Centrelink can provide the most comprehensive single source of National information about the number of individuals seeking funding with a diagnosis of Autism or Asperger Disorder in Australia. It provides information about the minimum number of individuals living with these diagnoses each year.”
- “The report's core finding gives the best indication of the likely number of people with ASD in the Australian population because primary school aged children are the group of children most likely to be recognised as having an ASD.”
- “... there is an estimated prevalence of autism spectrum disorders across Australia of 62.5 per 10,000 for 6-12 year old children. This means there is one child with an ASD on average in every 160 children in this age group which represents 10,625 children aged between 6 and 12 years with an ASD in Australia. ...”

# AABASD's prevalence report (2007) ... cont.

***“The report’s core finding could be extrapolated to suggest that with a prevalence rate of 62.5 per 10,000 there could be as many as 125,000 people with ASD in Australia ... ”***

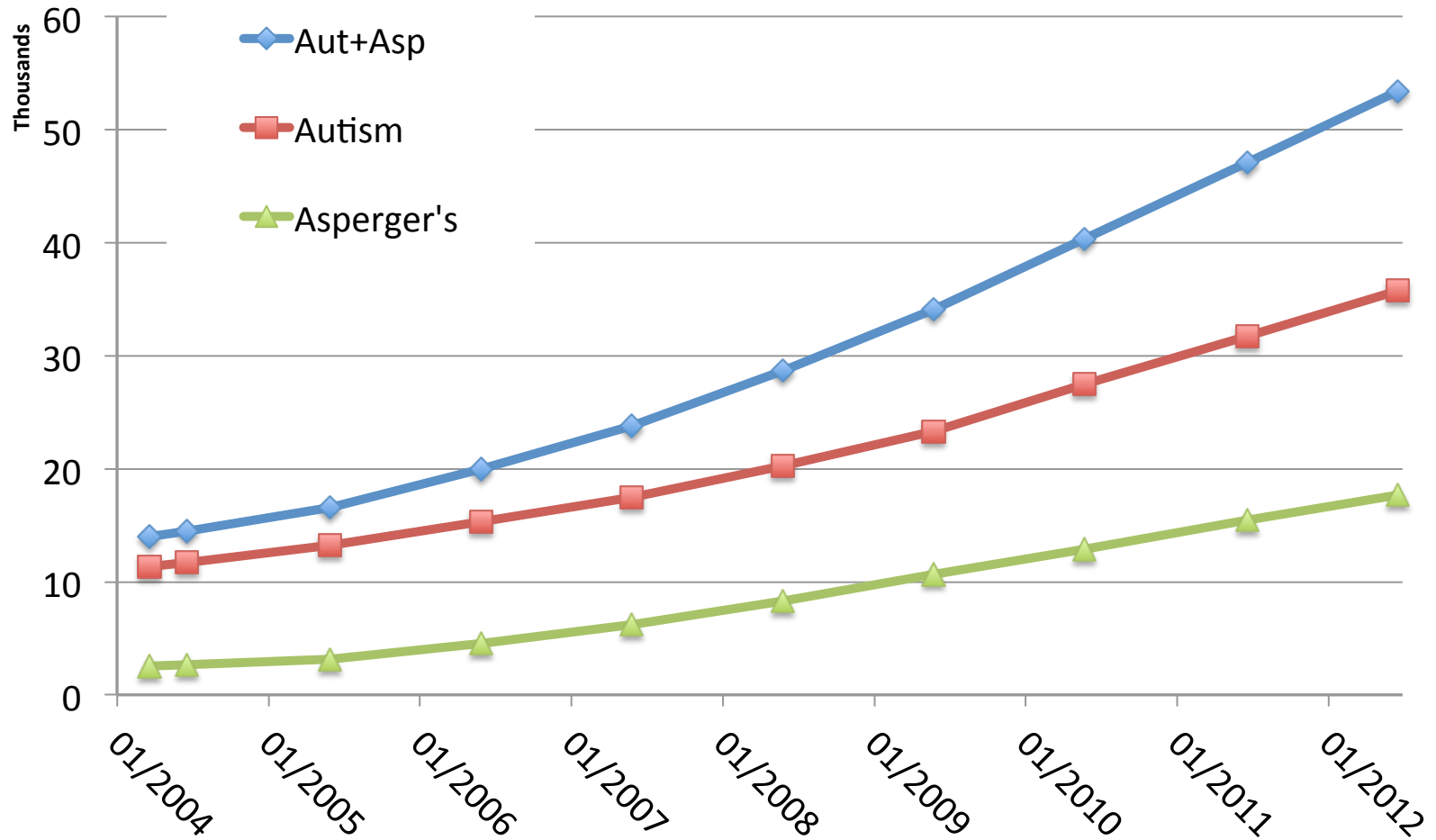
This prevalence estimate should **not** be extrapolated ...

- peak 62.5 per 10,000 was for children aged 6-12 years
- data from 2005 does not describe other periods
- does not estimate children in the 6-12 age range who are yet to be diagnosed (may remain undiagnosed, or not apply for Carer Allowance) ... nor allow for false positives. No PDD-NOS.

AABASD revised its estimate to 1% (1 in 100) based on 2009 data

... and now, we have data for 2012.

# Australia: Carer Allowance (Autistic & Asperger's <16 years old)

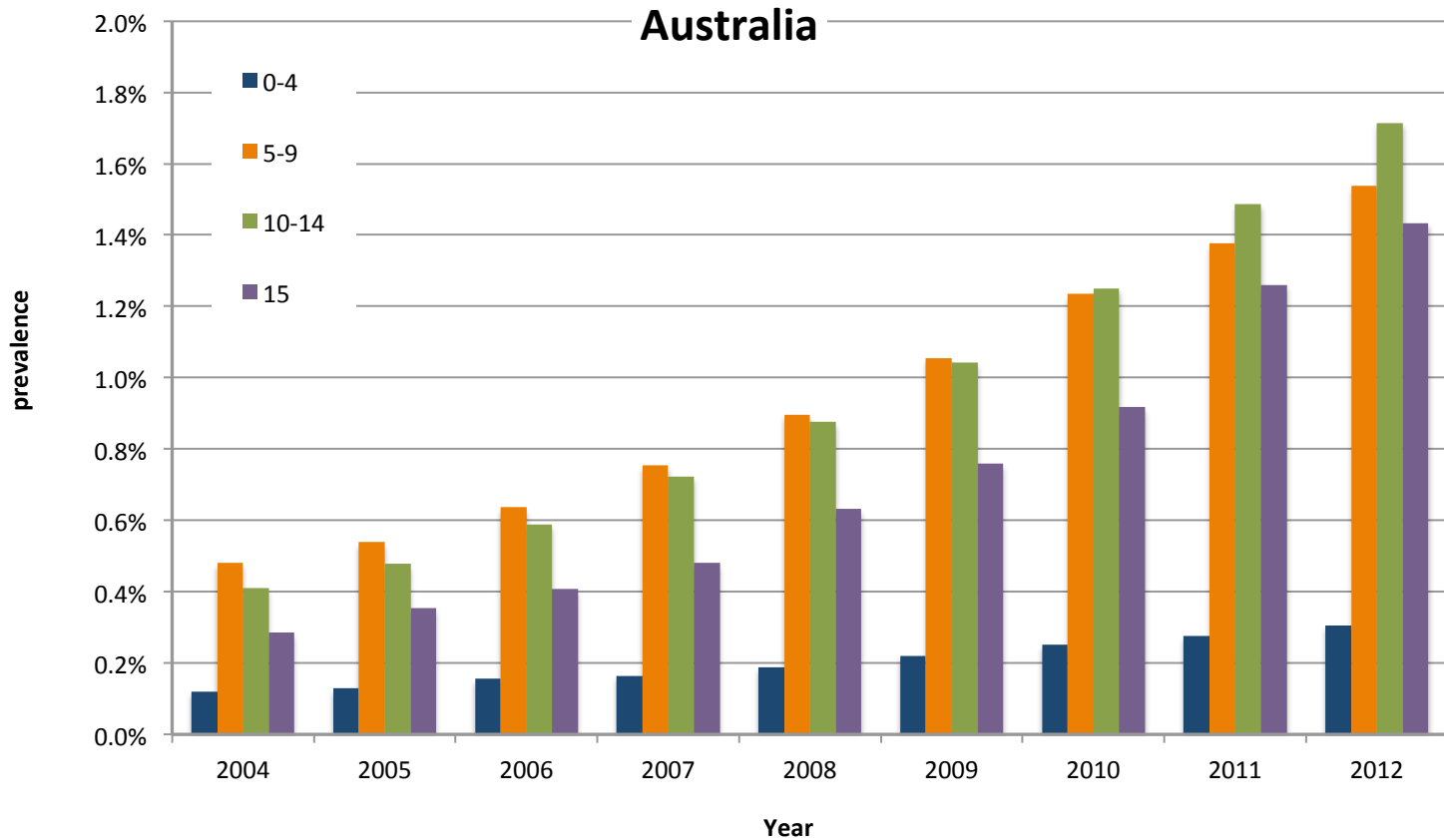


# Reason for Increase?

- Yes, the number of children diagnosed with autism spectrum disorders is increasing alarmingly.
- No, I do not know why.

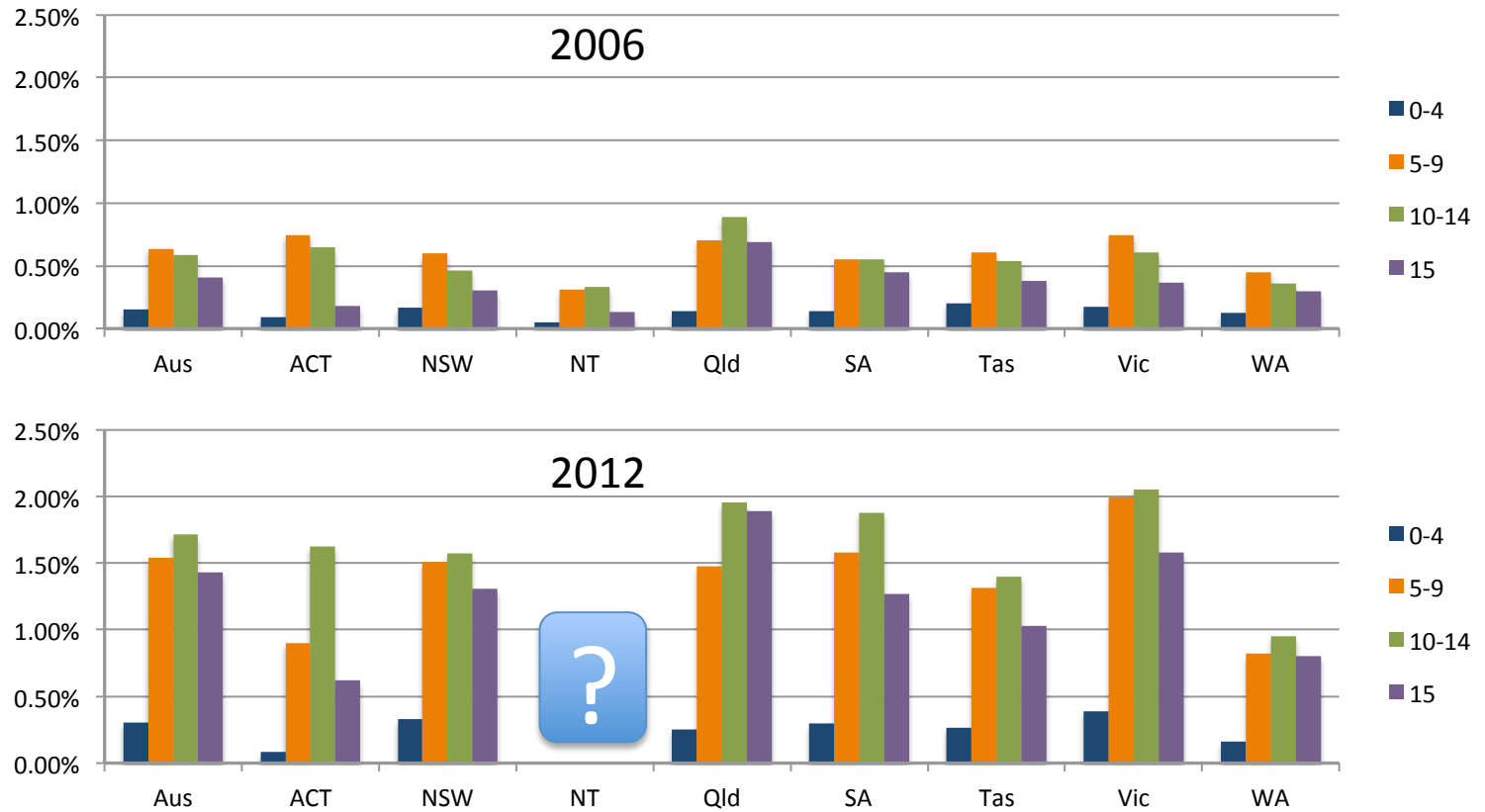
*People lost their careers just by expressing an hypothesis.*

# Carer Allowance (Child) Prevalence by age group





# State breakdown

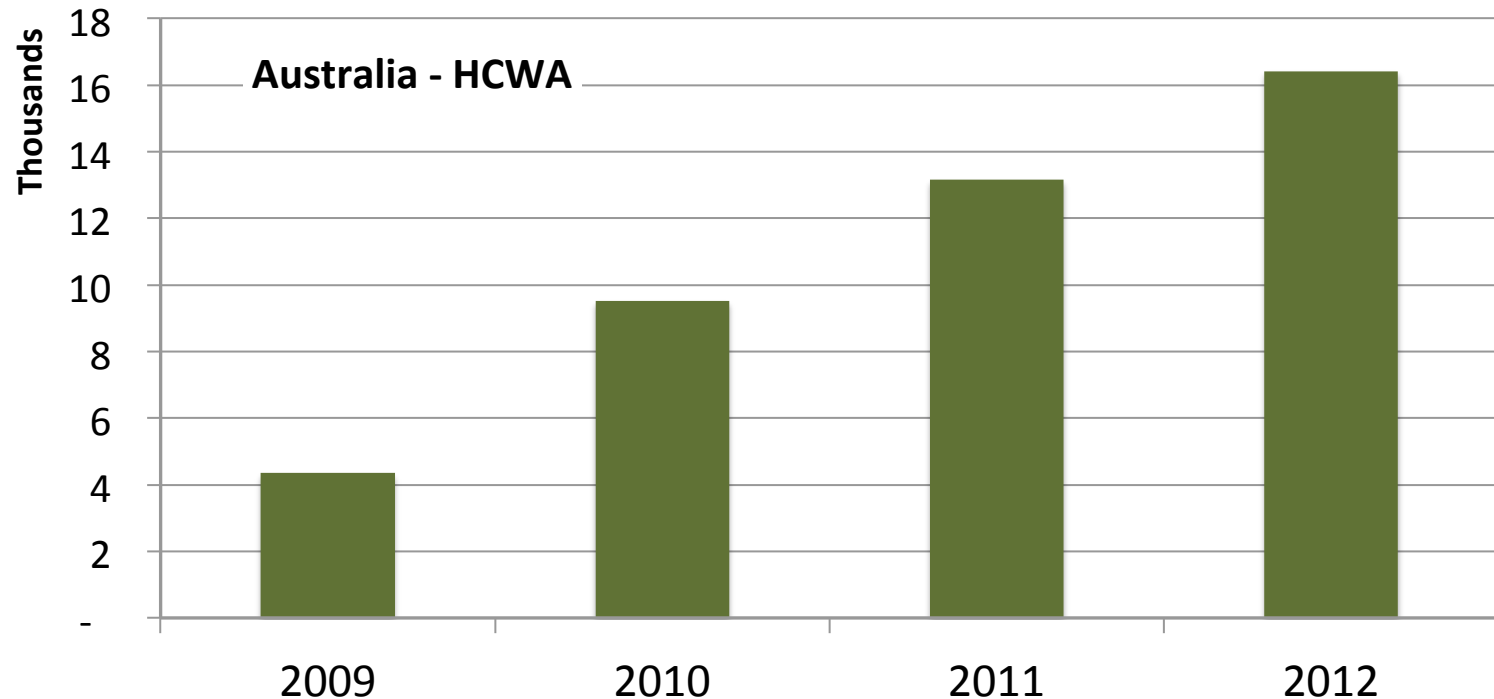


# Helping Children with Autism (HCWA)

- Provides \$12,000 for early intervention over 2 years
- Children diagnosed under 7 years of age, by paediatrician, child psychiatrist or pre-existing multi-disciplinary team
- This is **population data**: includes *most* ...but does not include everyone (low numbers for children diagnosed at age 6 years).
- Includes all (5) diagnoses in PDD

# HCWA aged 0-6 years

- Started in October 2008, numbers at 1<sup>st</sup> July so 2009 count is for the first 9 months ...



# Helping Children with Autism

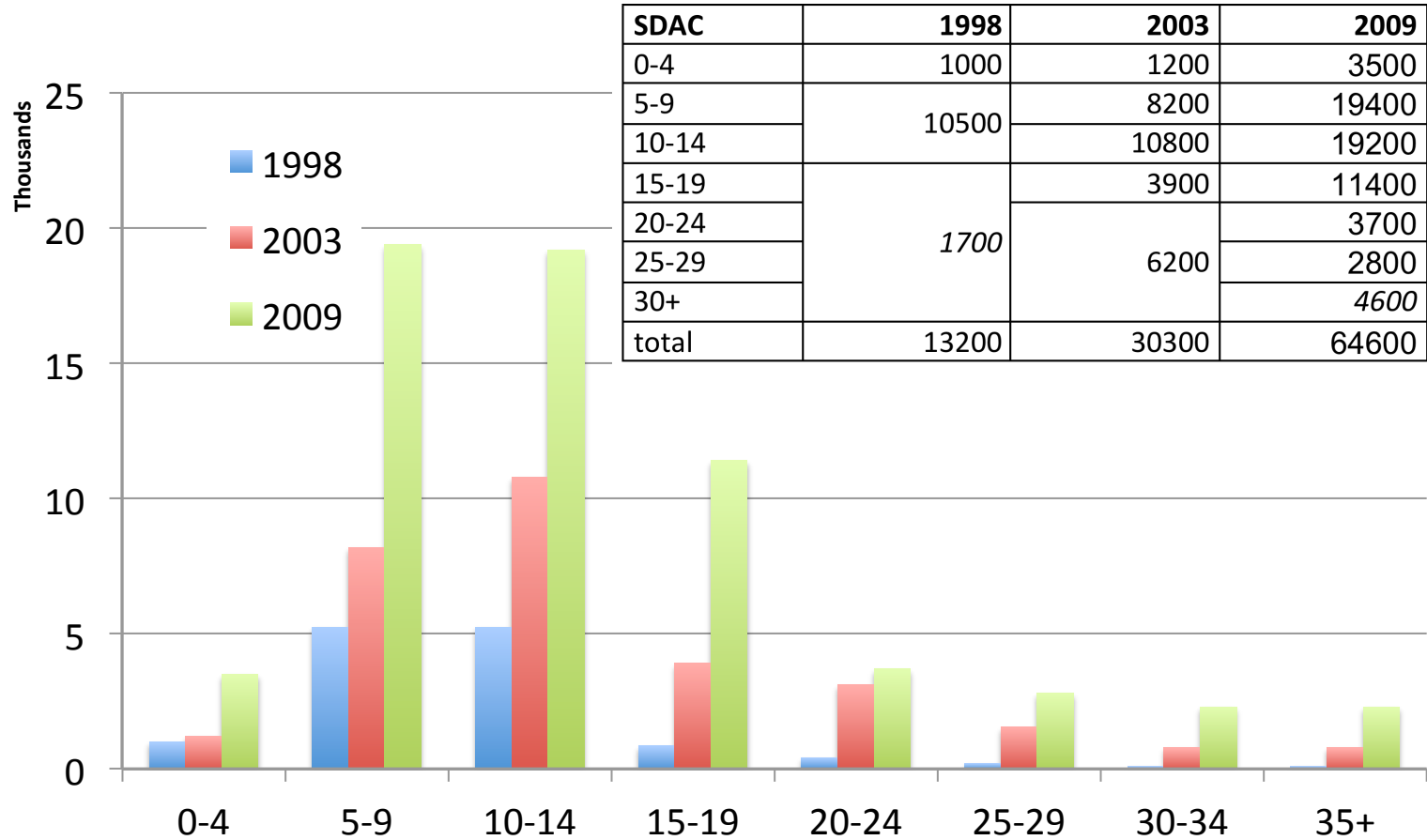
Primary Disability	Registered by 1 Jul 2009	Registered by 1 Jul 2010	Registered by 1 Jul 2011	Registered by 1 Jul 2012
Aspergers Disorder	28	100	136	851
Autistic Disorder	4,227	9,357	14,572	19,184
PDD-NOS	86	208	317	1,193
CDD & Rett's Disorder	<20	<20	<20	20

- Very low Asperger's Disorder under age 7 years, there are more PDD-NOS in this age range
- CDD & Rett's Disorder remain "rare"
- Big jump in Asperger's and PDD-NOS from 2011 to 2012?

Australian Bureau of Statistics (ABS)  
Survey of Disability, Ageing and Carers (SDAC)

- 2009 survey: 63,500 households (self-reporting when possible); 9,500 establishments (information from staff)
- Surveys all disabilities
- Data collected in 1998, 2003 and 2009 ...
- Data used widely, e.g. in modeling for NDIS, burden of disease and injury, ...
- *Autism/ASD is not a category in standard SDAC reporting*
- Specific report on autism from 2009 data (1998 and 2003 autism data in 2004 proceedings)

# ABS SDAC 1998-2009



# SDAC autism report

More than counting numbers ...

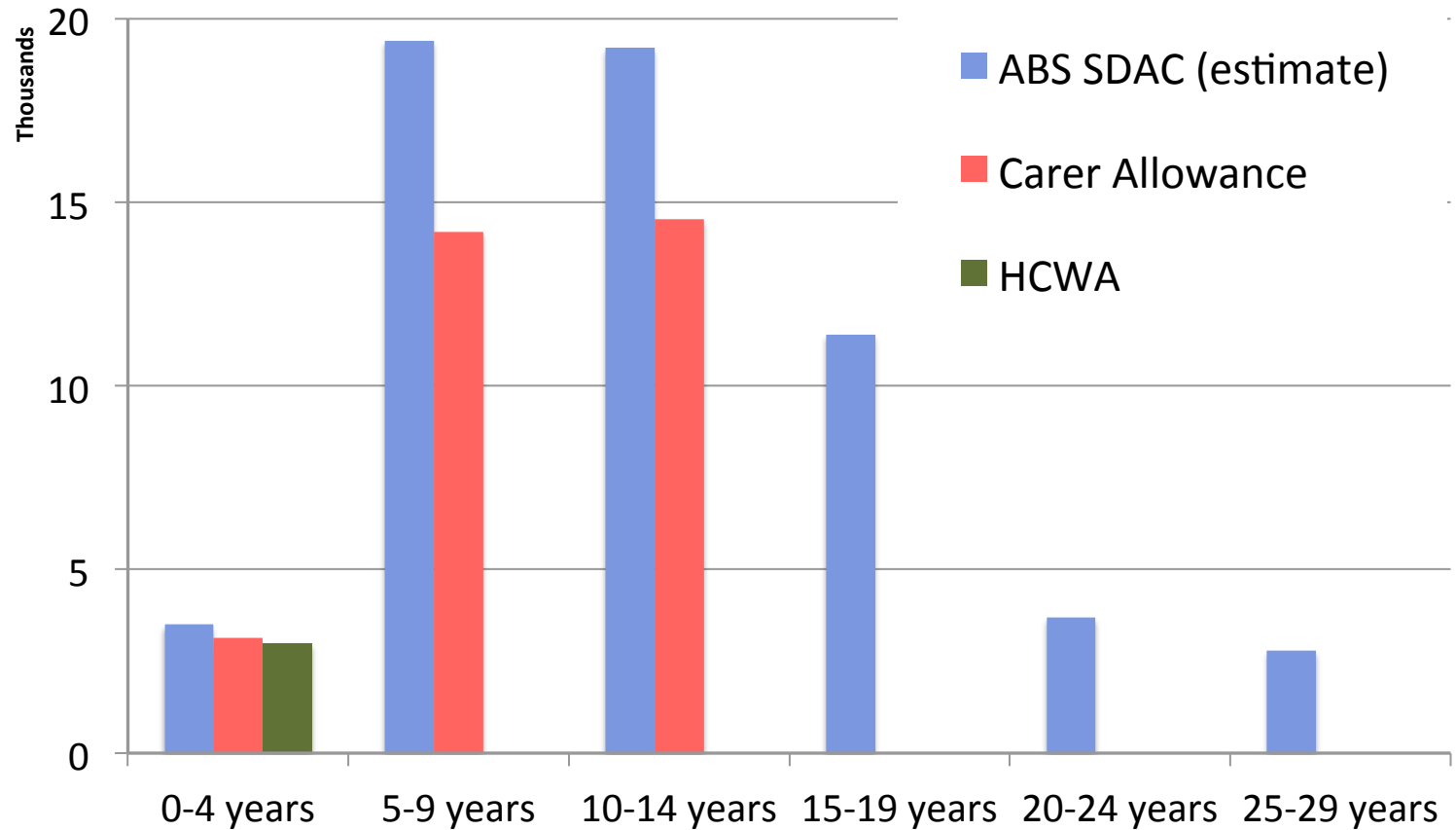
- Severe and profound disability
  - 2003: 87% with severe or profound disability
  - 2009: 74% with severe or profound disability

*So ... some increase is milder cases (13%), but **most** growth is people with severe & profound disability*

- Abysmal outcomes for PwASD in education, labour force participation, disability services, ...  
*check it out*

<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4428.0>

# Compare 2009 data





# conclusions

- Autism prevalence estimates vary by age and time: we **cannot**
  - assume uniform prevalence
  - say “with a prevalence rate of 62.5 per 10,000 there could be as many as 125,000 people with ASD in Australia ...”
- substantial growth in PwASD registering for services
- ASD growth is mostly people with “severe or profound disability” (from measures of disability generally )
- ABS reports *abysmal* outcomes for PwASD: Australia must do better for PwASD
- different sources tell a remarkably consistent story
- more analyses and more datasets (e.g. CSTDA/NDA datasets, Medicare items, ...) can extend understanding of PwASD

# Acknowledgements

- ABS for providing unpublished data on autism
- FaHCSIA
- A4 Management Group
- SOfASD in the ACT
- AABASD Directors
- Colleagues at JCSMR ANU

Thank you

for your interest