

2^{es} rencontres
scientifiques
de la CNSA pour
l'autonomie

15 et 16 février
2012 - Paris

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Patricia Howlin

What does the future hold for adults with autism?

Patricia Howlin, Institute of Psychiatry, King's College, London

KING'S
College
LONDON

University of London

Focus of presentation:

- * **1. Review of recent outcome research**
- * **2. Presentation of data from 40 year follow-up study**
(Howlin, Rutter et al.)
 - Changes over time
 - Levels of independent living; jobs relationships
 - Factors related to outcome
- * **3. Implications for the future**

Most autism research focuses on children



*** But autism does not disappear
at age 18!!**



think differently about autism
campaign with us



Transition to adulthood: Positive aspects

- * **Overall reduction in autism symptomatology from child-adulthood (majority show < scores on ADI; only minority worsen)**
- * **Decrease in repetitive and stereotyped behaviours in older adults (22-50 years)**
- * **Improvement in social reciprocity in adolescents/ young adults (10-21 years)**
- * **Decrease in problem behaviours: some follow-up studies = 30 to >40% of participants show marked improvements in late adolescence/early adulthood**

Kanner, 1973;; Howlin et al., 2004; Mawhood et al., 2002; Farley et al., 2009; Seltzer et al., 2009; 2010

But outweighed by negative aspects:

* **Adult Psychiatric Morbidity Survey, 2007; Brugha et al.**

* **Prevalence:**

Total population 1% (1.8% males; .2% females) N~ 400,000
in UK

* **As a group (including those of normal IQ)**

Socially disadvantaged; unmarried, living on benefits and in
social housing

Educationally less well qualified

Under-supported by social, educational, welfare and health
services

In the lowest quintile for social deprivation

Transition to adulthood: Negative aspects

- * **Life time per capita cost of autism: £3.1 million for high-functioning individual; £4.6 million for low-functioning**
(Knapp, et al., 2009)
- * **Low rates of employment (~60% in sheltered workshops/day centres)**
- * **Adult day activities lower quality than educational activities in school**
- * **Adults of normal IQ significantly LESS likely to have a structured day time activity than those with intellectual impairment** (Seltzer et al., 2009; 2010; Howlin et al., 2004)

Transition to adulthood: Negative aspects

* Increase in mental health diagnoses (mainly depression & anxiety)

USA: 42% of adolescents; 51% of adults

UK: 22% developing **new** psychiatric problems (mainly in late teens/ early adulthood)

* Increase in use of medication over time

USA study: 64% of adolescents; 88% of adults on at least one medication; 18% of adolescents, 49% of adults on 3 or more meds

* Once begun medication unlikely to stop

(Seltzer et al., 2009; 2010; Howlin et al., 2004; Hutton et al., 2009)

Systematic review of adult follow-up studies (Howlin & Moss, 2012)

* **23 studies: 1967-2010**

* **Sample size: mean n= 68 (range 11-241)**

* **Age: mean = 24 years (range 16-60 yrs)**

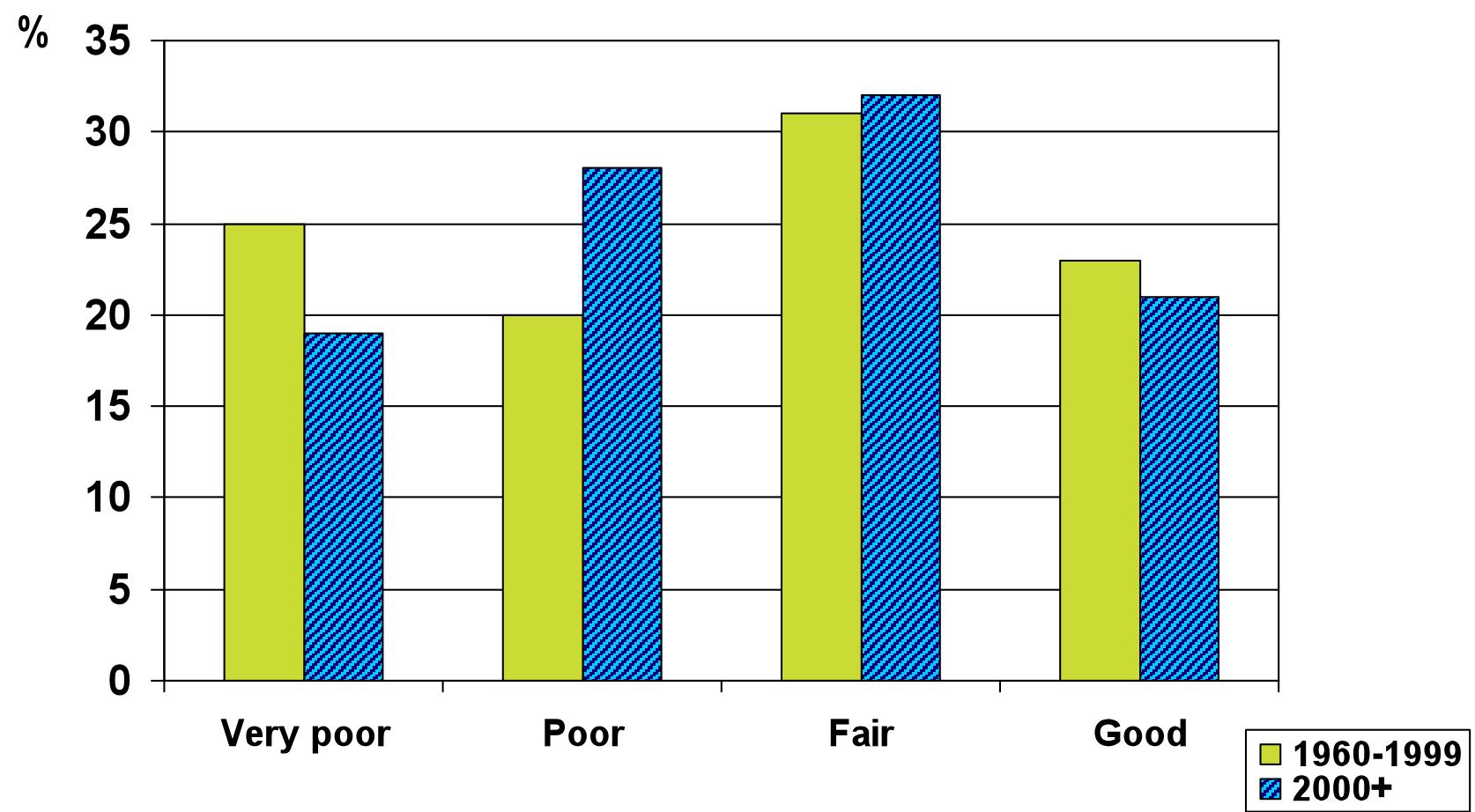
* **Child IQ: <30 to 140**

* **Outcomes:**

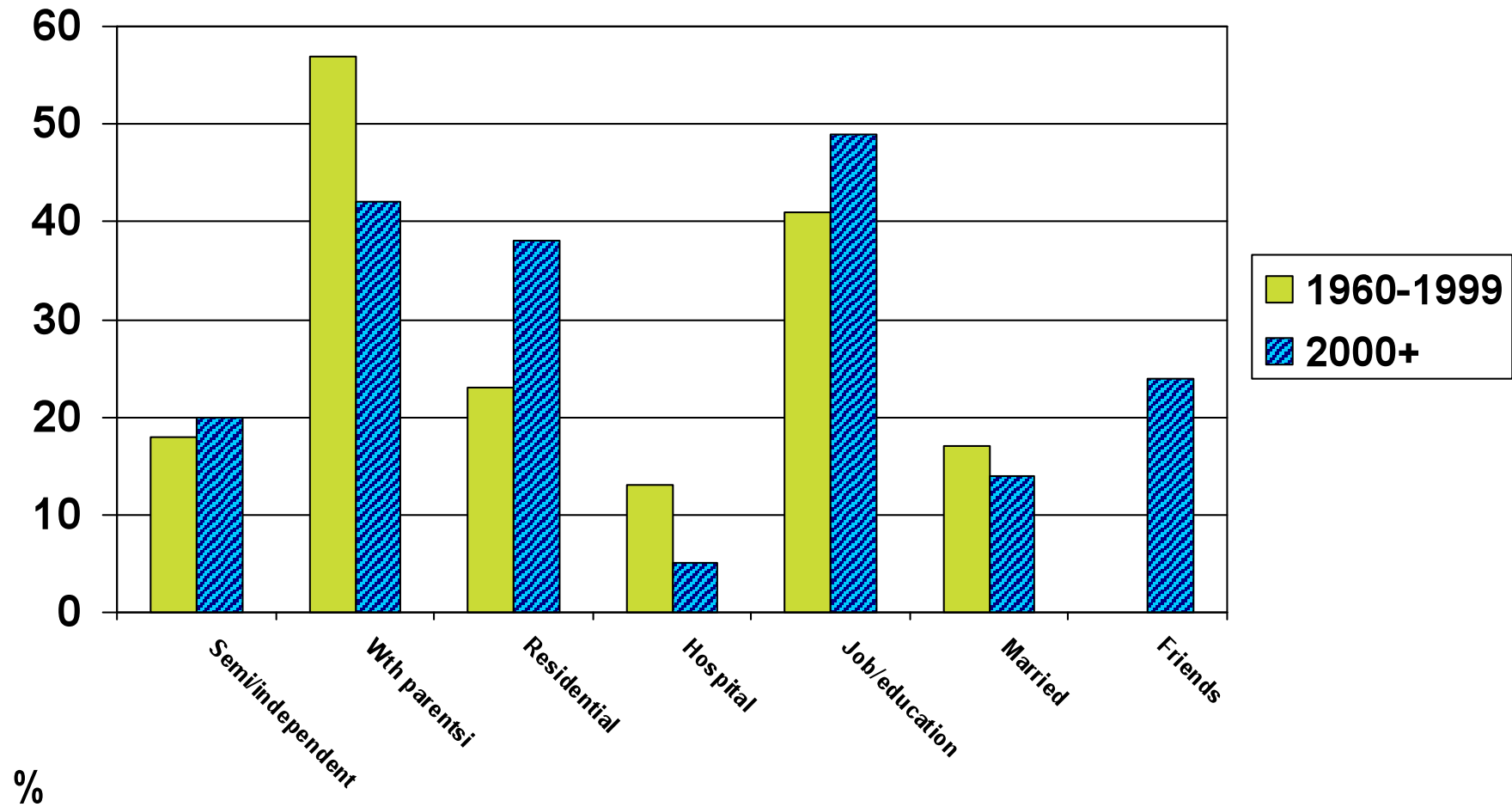
Good/very good: mean 21% (range 0-69 %) Fair : mean
32% (range 11-75%)

Poor/very poor: mean 46% (range 12-78%)

Systematic review of adult follow-up studies (Howlin & Moss, 2011) Overall social outcomes – 1967-1999; 2000-2011



Work, independence and friendships 1967-1999; 2000-2011



40 year follow-up study- (Howlin, Goode & Rutter, 2004-2011)

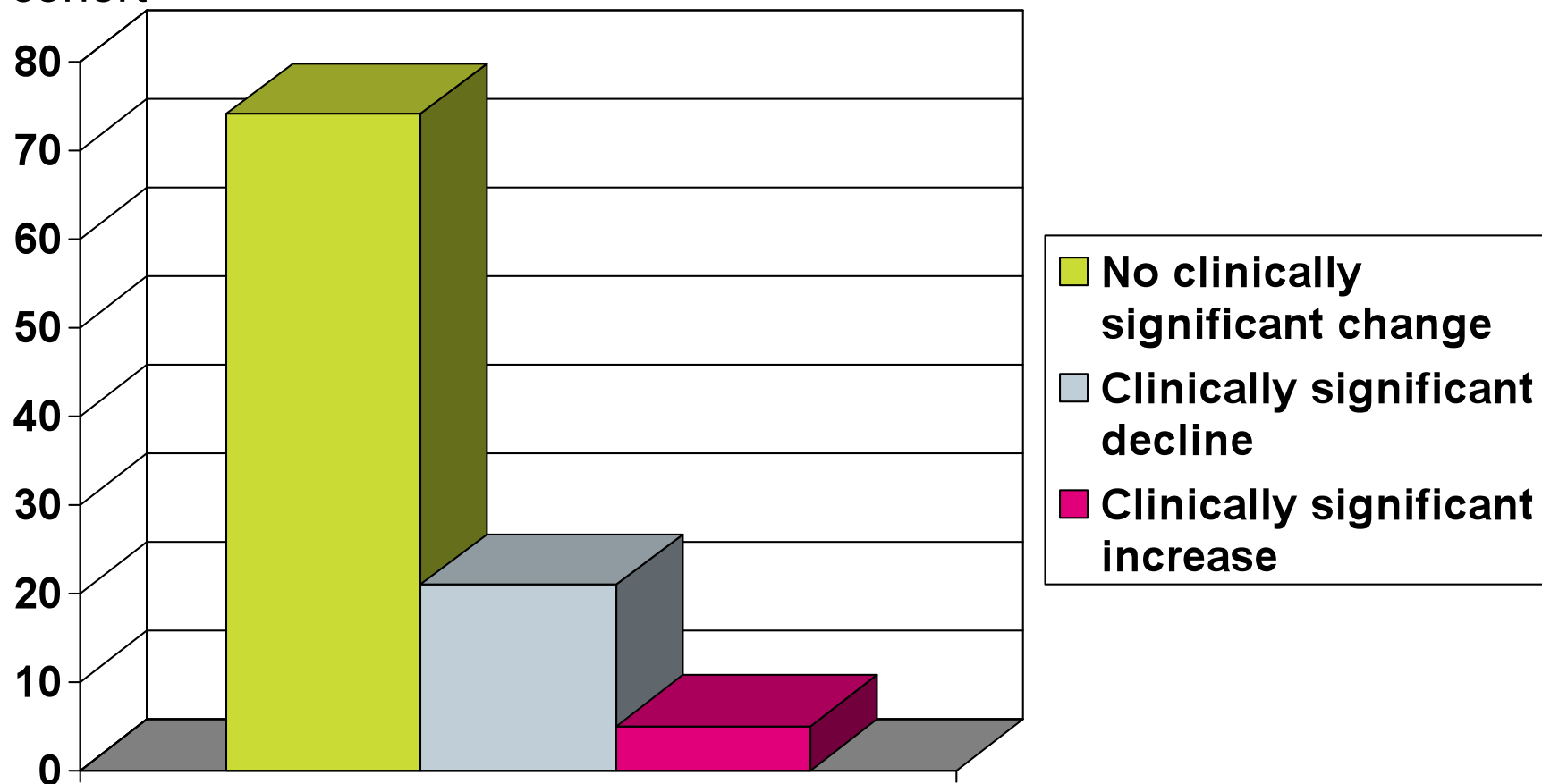
- * 60 individuals; all PIQ \geq 70 in childhood
- * Mean age first seen= 6.6 yrs (3-13 yrs)
- * 11 follow up- mean age= 29 years (16-45 yrs)
- * Current follow-up- mean age 44 years (29-64 yrs)
- * Diagnosis confirmed with ADI-R* at follow-up
- * Also assessment of 90 siblings

*Autism Diagnostic Interview (revised)

Current adult status

IQ: stable for most individuals from child to adult - significant decline in a few

% cohort



Language

- * **70% using phrase/ sentence speech but**
- * **Only 20% above 18-19 year ceiling on tests of expression and comprehension**
- * **No significant difference between expressive and receptive language**

Employment

*Jobs:

14% in professional/skilled non-manual work

18% in unskilled or manual jobs

68% sheltered employment/never worked

36% currently in work

8% out of work

56% never worked

Social relationships

* **Current friendships (own age group)**

7% ≥ one reciprocal relationship

10% some friends but limited reciprocity/duration

77% no specific friendships

* **Close sexual relationships (ever)**

9% close relationship/marriage now or in past

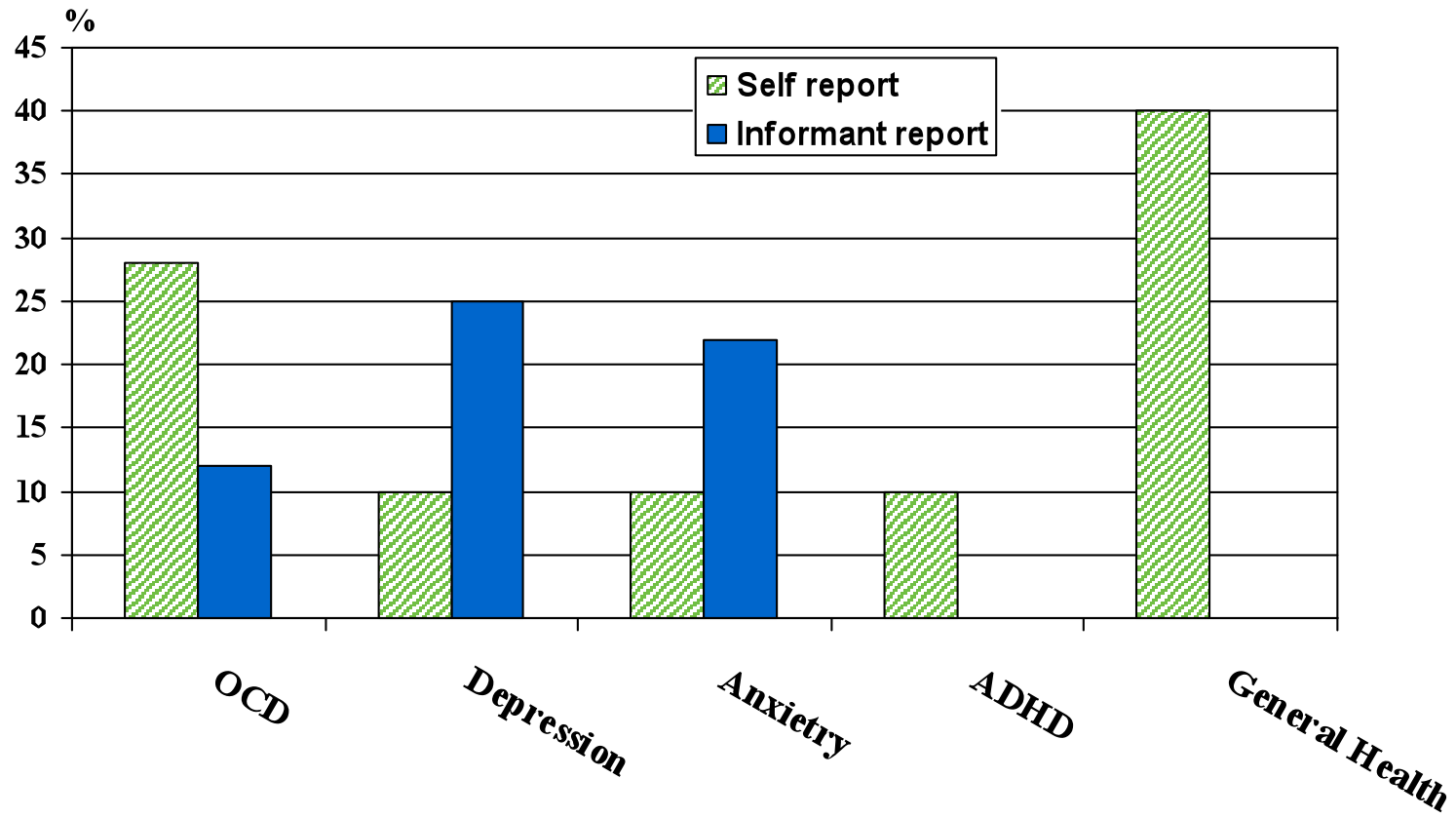
15% close relationship but limited duration/reciprocity

77% never had close reciprocal relationship

Independence

- * **13% living independently**
- * **13% in semi sheltered accomm/ at home but high level of autonomy**
- * **17% at home - little autonomy**
- * **20% residential unit – little autonomy**
- * **33% autism unit**
- * **3% hospital care**

Mental Health Problems

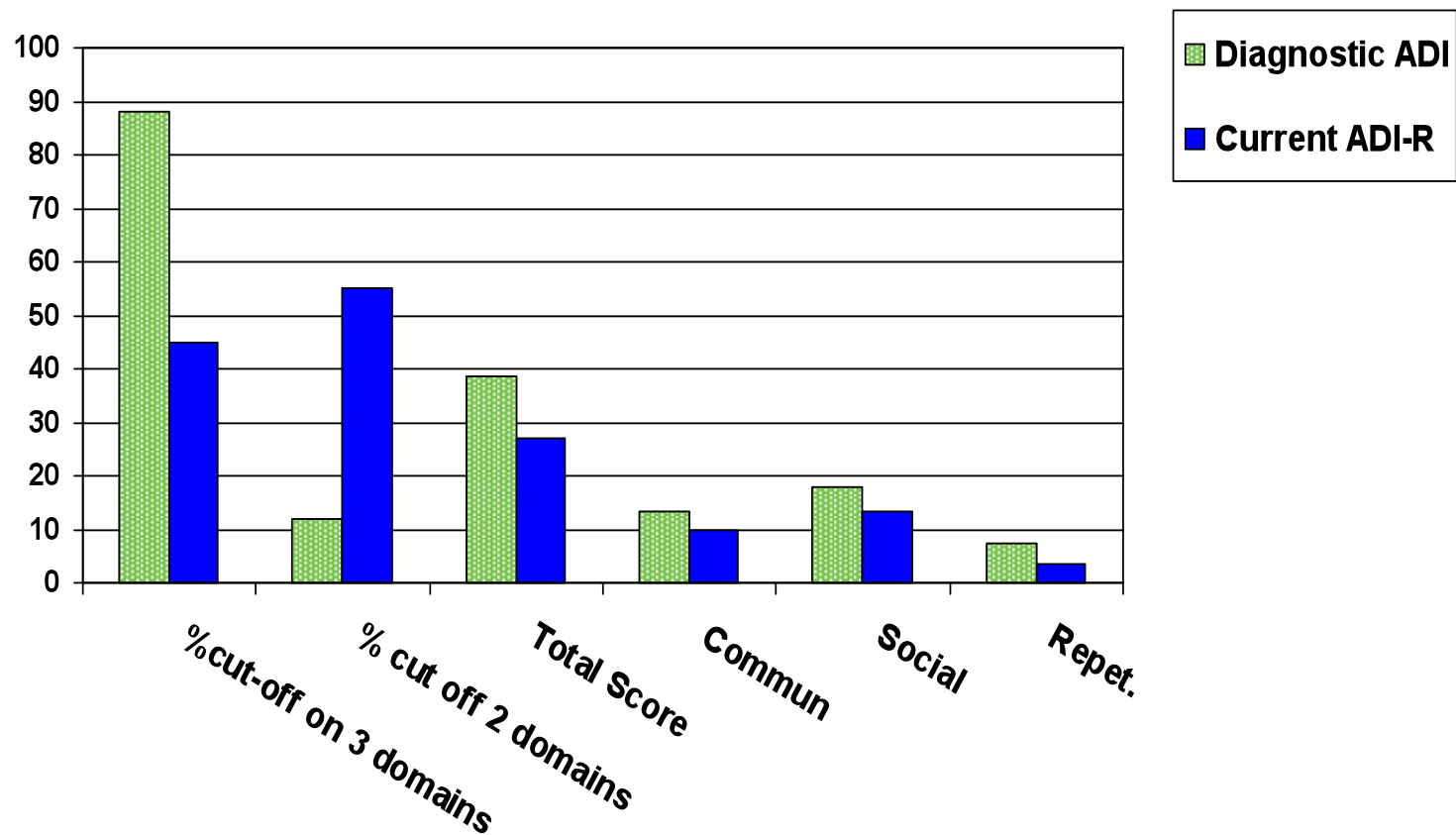


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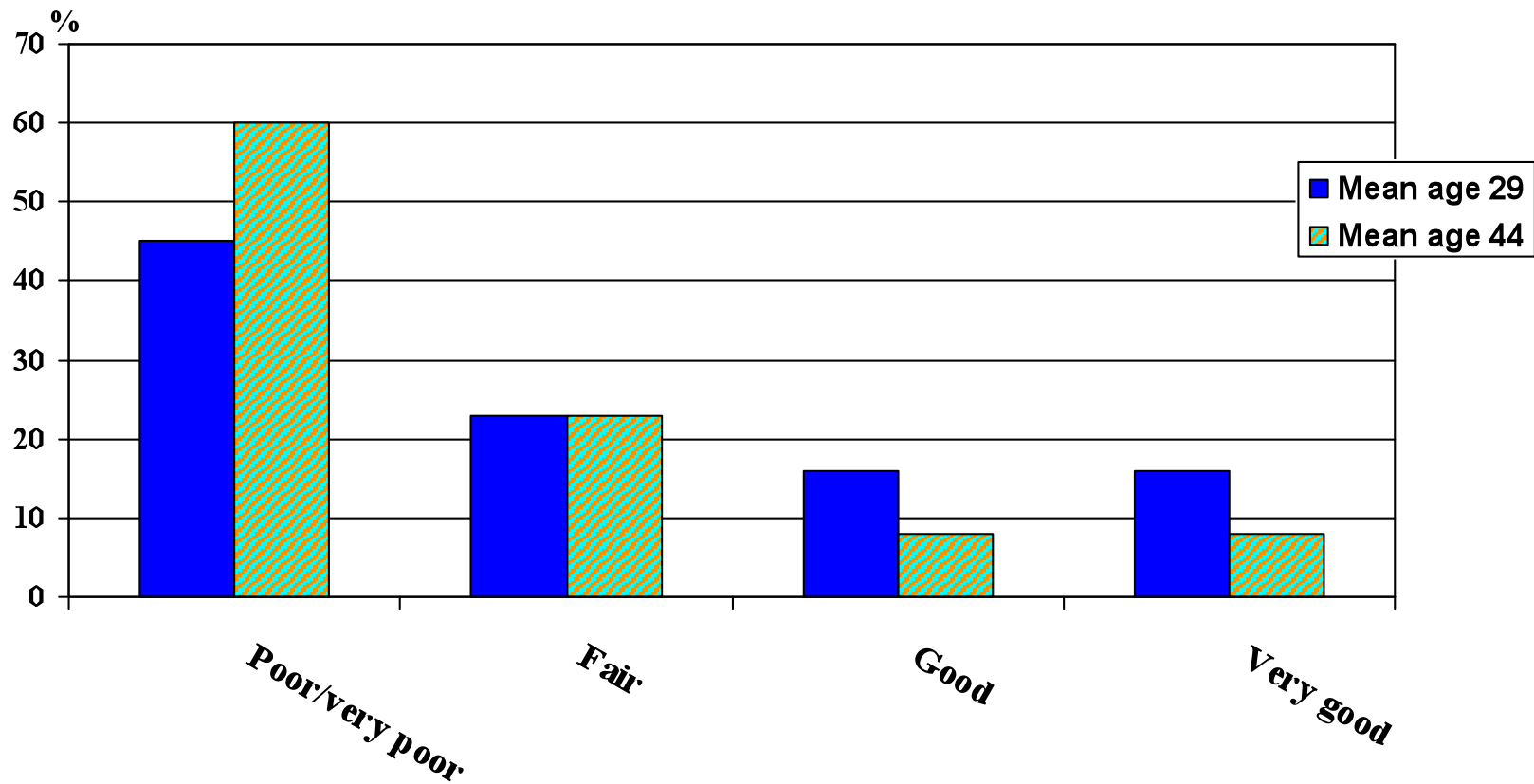
Change over time

Symptom severity (ADI/ADI-R) change

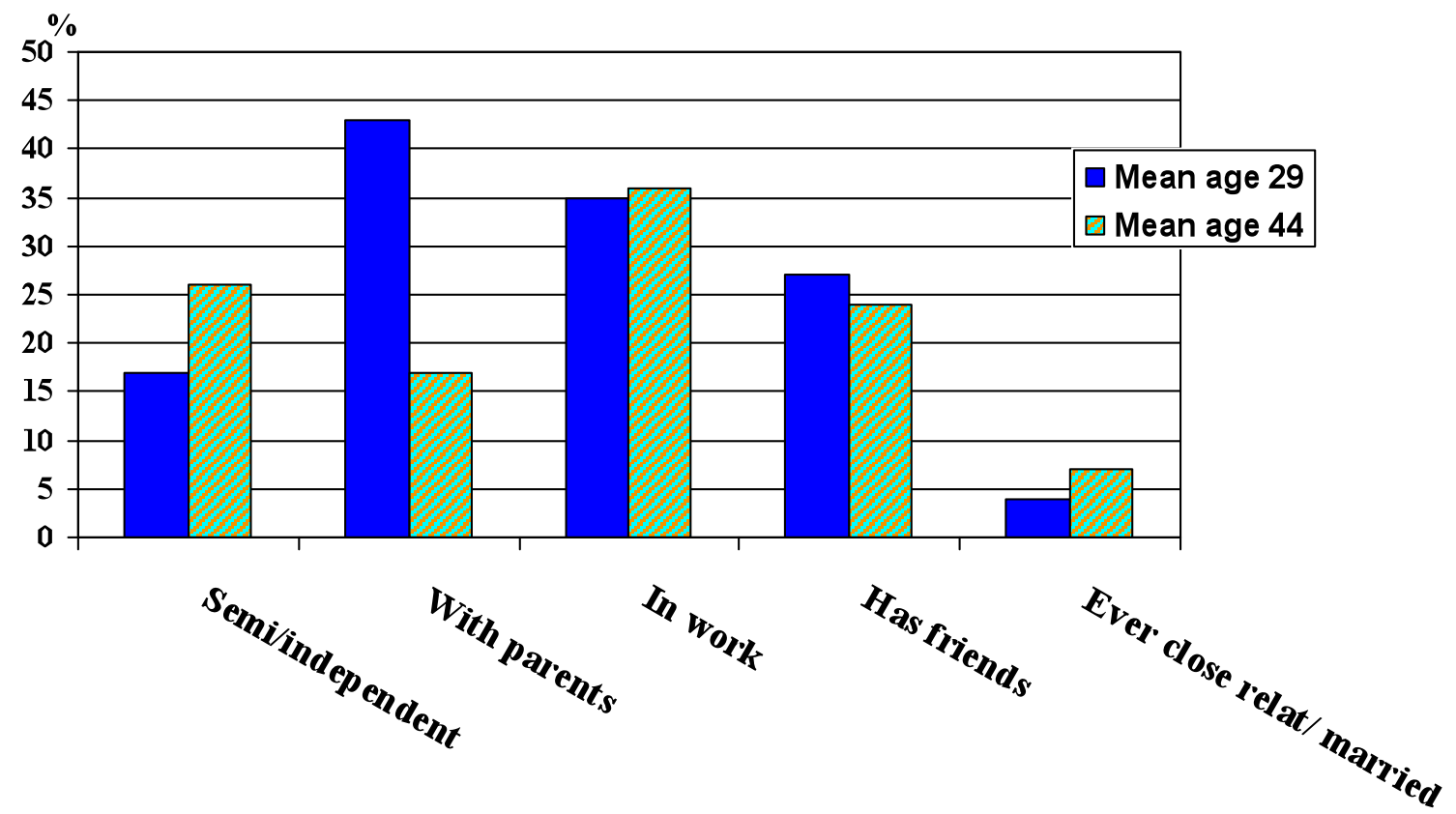


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Changes in overall outcome ratings in adulthood (20's to mid 40's)



Change in independent living, work & relationships



Main predictors of poor adult outcomes adult outcome:

- * Continuing deficits in language post childhood (but not language regression)
- * Severe behavioural problems (e.g. aggression)
- * Long-term hospital care
- * Sex (but n females small)
- * Very impaired social abilities in childhood

But large individual variation

**Male – 55 yrs old; child PIQ
80 (no verbal IQ score);
Adult PIQ 113; VIQ > 130**

**As child treated as in-patient
for some time**

**No other specialist
intervention;**

**Educated in Intellectual
Disability & mainstream
schools**

**As adult- MSc degree;
employed for many years,
married in past; has group
of friends**

**Female - 47; child PIQ 87.
Age 30 yrs PIQ 57. Current
IQ VABS only (IQ
equivalent 20)**

**As child limited language (?
Regression)**

**Educated in specialist autism
provision**

**As adult- private residential
home; little autonomy.
Never worked; no friends**

Siblings

*Majority:

Living independently

High levels of employment

Married/in relationships

*However:

A minority still living with parents

Difficulties with employment/social relationships

Mental health problems (anxiety, OCD, depression)
higher than in general population especially amongst
sisters

Family concerns

- * Parents are a “hidden army” of carers- often they and their sons/ daughters unknown to social and other services
- * “What will happen when we are no longer there to care?” (80 yr old mother; 90 yr old father)
- * “ I will have to take over when parents go- but don't know how (sibling) will cope; or how I will fit it in with my own family needs” (40 yr old sister)
- * “He still goes to my mother's care home every day, expecting her to tell him what he should buy/do etc” (sister of 50 yr old man; mother with Alzheimer's)

Conclusions:

*** At an individual level – positive findings with respect to stability of IQ; improvements in language, reduction in severity of autism symptoms**

But

*** At a societal level failure to provide the support and structures necessary to enhance social functioning and independence**

Implications: Need to..

- * **Improve support for transition from child to adult services**
- * **Increase recognition by social, health and employment services of needs of adults with autism (especially those who are more able)**
- * **Fill the gap between learning disability & adult mental health services- many people with ASD don't meet criteria for either**
- * **Remove pressures on parents**
- * **Significantly improve funding for all stages of life**