



Involving families in clinical research, changing ASD research capacity

Jeremy Parr, Newcastle, UK



Overview

Background to Daslⁿe and ASD-UK

- Recruitment methods
- Governance

Progress with recruitment; challenges

Data: Representativeness, research, engagement with families

Clinical utility of data; utility for service development

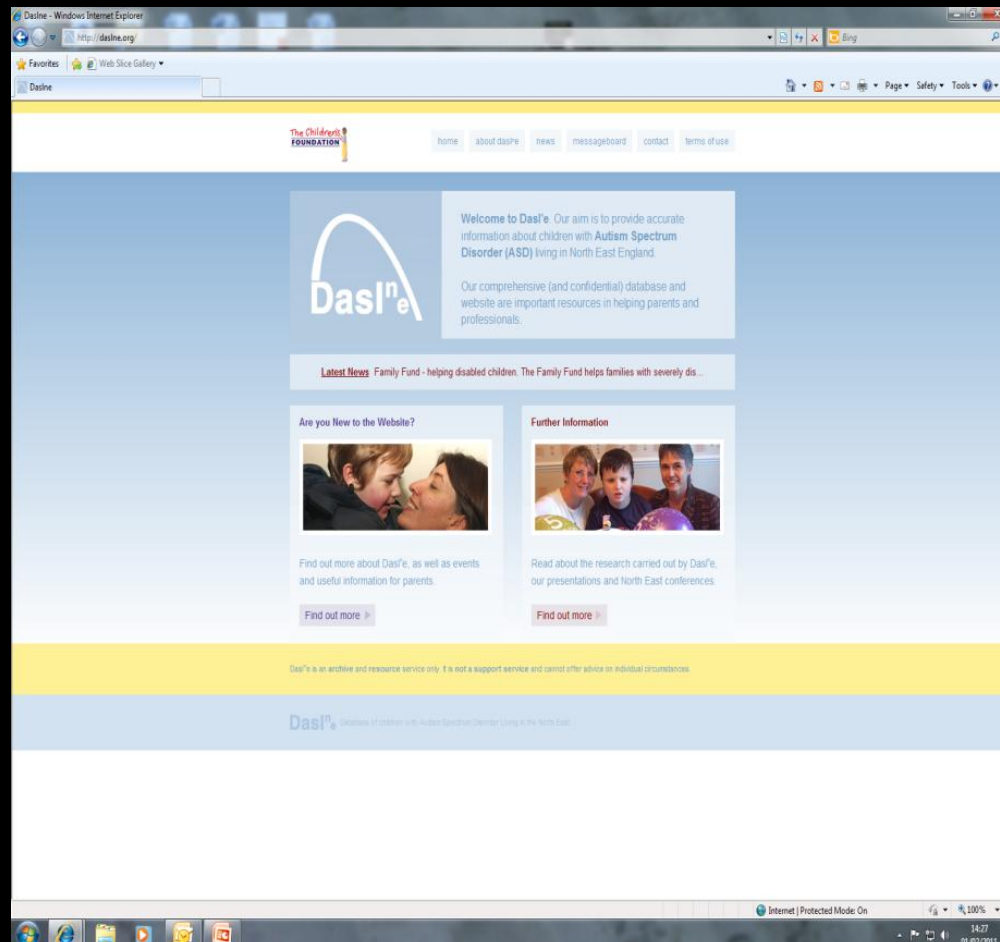
Moving forward in 2015-17

Historical context: The Database for children with ASD living in the North East (Dasl^{ne})

Dasl^{ne}: the challenge of developing a regional database for autism spectrum disorder

H McConachie,¹ R Barry,² A Spencer,¹ L Parker,³ A Le Couteur,¹ A Colver¹

Arch Dis Child 2009;**94**:38–41. doi:10.1136/adc.2007.126326



Started 2003

1350 families ~ 60%
ascertainment across 6
areas of North East England

Population sampling frame;
representative

Supported recruitment to
25 research studies

www.daslne.org



ASD-UK aims

Improve infrastructure & increase capacity for ASD research

- Increasing families' opportunities to participate in research
- Increasing numbers of children (up to 17 years) available to UK researchers

**Facilitate high quality research
that aims to make a difference to families**

ASD-UK Participating centres 2011-12



9 Groups

32 NHS Trusts

**Durham, Darlington
& Teesside – 3 Trusts**

Sheffield – 1 Trust

Nottingham & Derby – 2 Trusts

Norwich – 1 Trust

Berkshire & Northants – 3 Trusts

N. Thames – 10 Trusts

S. Thames – 6 Trusts

Bristol & Somerset – 3 Trusts

Cardiff – 1 Trust

Addition of new centres 2012-13

15 Groups
55 NHS Trusts

Belfast
Yorkshire
North West
Midlands
South West



Durham, Darlington &
Teesside
Sheffield
Nottingham & Derby
East Anglia
Berkshire
North Thames
South Thames
Bristol & Somerset
Cardiff

January 2015

16 Groups
70+ NHS Trusts

Glasgow
and
Lothian

Belfast

Yorkshire

North West

Midlands

South West



Durham, Darlington &
Teesside

Sheffield

East Midlands

East Anglia

Berkshire

North Thames

South Thames

Bristol & Somerset

Cardiff

Recruitment

We identify families through:

- Clinic appointments
- Local lists of children previously diagnosed (inc education)
- Self referral

Recruitment

Families identified at NHS clinic appointments:

- we offer all families the opportunity to participate (timing)
- clinicians give information sheet & complete 'contact form'

Contact form:

child's name, NHS number, year of birth, gender, diagnosis,
parents/carers' contact details

Families who do not want to take part:

complete reverse of contact form: year of birth, gender, diagnosis, postcode

Local agreements with Education
(Voluntary sector)

On receipt of 'contact' form

- Parents received a study pack including:
 1. consent to be contacted about research projects
 2. parent questionnaire
 3. SCQ

(30-40 mins)

- Return with diagnostic & education reports (or consent for us to access these from NHS Trust)

Paper responses vs. web based consent and data system

Welcome to the Autism Spectrum Database - UK (ASD-UK)

ASD-UK is a UK research family database of children with an autism spectrum disorder (ASD). The aim of ASD-UK is to provide accurate data about children with an ASD to facilitate research and give families the opportunity to take part in research studies.

The project is funded by Autistica (www.autistica.org.uk). Autistica is a charity that is committed to ensuring that increased understanding and new scientific knowledge will improve the lives of individuals with ASD and their families.

The aims of ASD-UK

- To collect data about children with ASD and their families that will allow important questions about ASD to be addressed.
- To help researchers recruit families to studies about ASD that may lead to advances in the care and treatment of children.
- Allow families to take part in research that aims to answer important questions about ASD.

[Register with ASD-UK](#)[Log in to ASD-UK](#)[About ASD-UK](#)

Progress with recruitment

March 2011 – January 2015 (46 months)

2238 contact forms returned

- Clinics 1460
- NHS local lists of children 707
- Self referral 71

**1471 families have returned consent, 1384
have completed questionnaires**

Average 49 contact forms a month received

ASD-UK/DasI^{ne}

Progress with recruitment (to Jan 2015)



1470 families have returned consent & completed questionnaires; in touch with 2200 families

One family per day joins ASD-UK



1460 families; the worlds largest population based ASD database (55% of families)

Maintaining collaboration

Child health teams and organisations

- Visits & presentations; regional and national meetings
- Progress updates; publish data, make available
- Newsletters

Parents

- Parent committee; advise on methods, materials
- Website; publish data, make available
- Newsletters



Researchers

- Research committee to review applications
- Ensure independent from the lead team

Governance & research applications

ASD-UK is overseen by Steering Committee (includes clinicians, researchers and parents); data security paramount

Applications to recruit from ASD-UK are reviewed by research committee (researchers and parents)

Data analysis projects supported; in partnership preferred

Requirements for applicants

- Research question aiming to improve lives of those with ASD
- Study feasible in reasonable timeframe
- Peer review (unless already done)
- Ethics
- Small fee payable; staff time in contacting families, data access

Ensuring data quality

Updating data critical; database only successful if data of high quality

Researchers recruiting ASD-UK families are asked to:

- Share relevant information; for example, standardised assessments

ASD-UK team will:

- Contact families every 2-3 years to request update information (e.g. Non verbal / verbal; new SEN)

Evidence for ASD Recurrence Rates and Reproductive Stoppage From Large UK ASD Research Family Databases

Autism Research ••: ••–••, 2014

Claire L. Wood, Frances Warnell, Mary Johnson, Annette Hames, Mark S. Pearce, Helen McConachie, and Jeremy R. Parr

Results

Recurrence Rate of ASD in the Current Whole Daslⁿe and ASD-UK Cohorts

Seventy-nine (6.0%) of the 1320 Daslⁿe families and 77 (7.7%) of the 1,000 ASD-UK families on whom data were available had two or more siblings with ASD in a nuclear family; ten of these 77 ASD-UK families had three or more children with ASD. On initial registration with ASD-UK, 55% of parents reported that they had relatives with “similar but milder difficulties to ASD” but did not have an ASD diagnosis. Twenty-seven percent of parents reported that there was an extended family history of ASD (data about which relative was affected were not requested for ethical reasons).

Emotional and Behavioural Problems in Children with Autism Spectrum Disorder

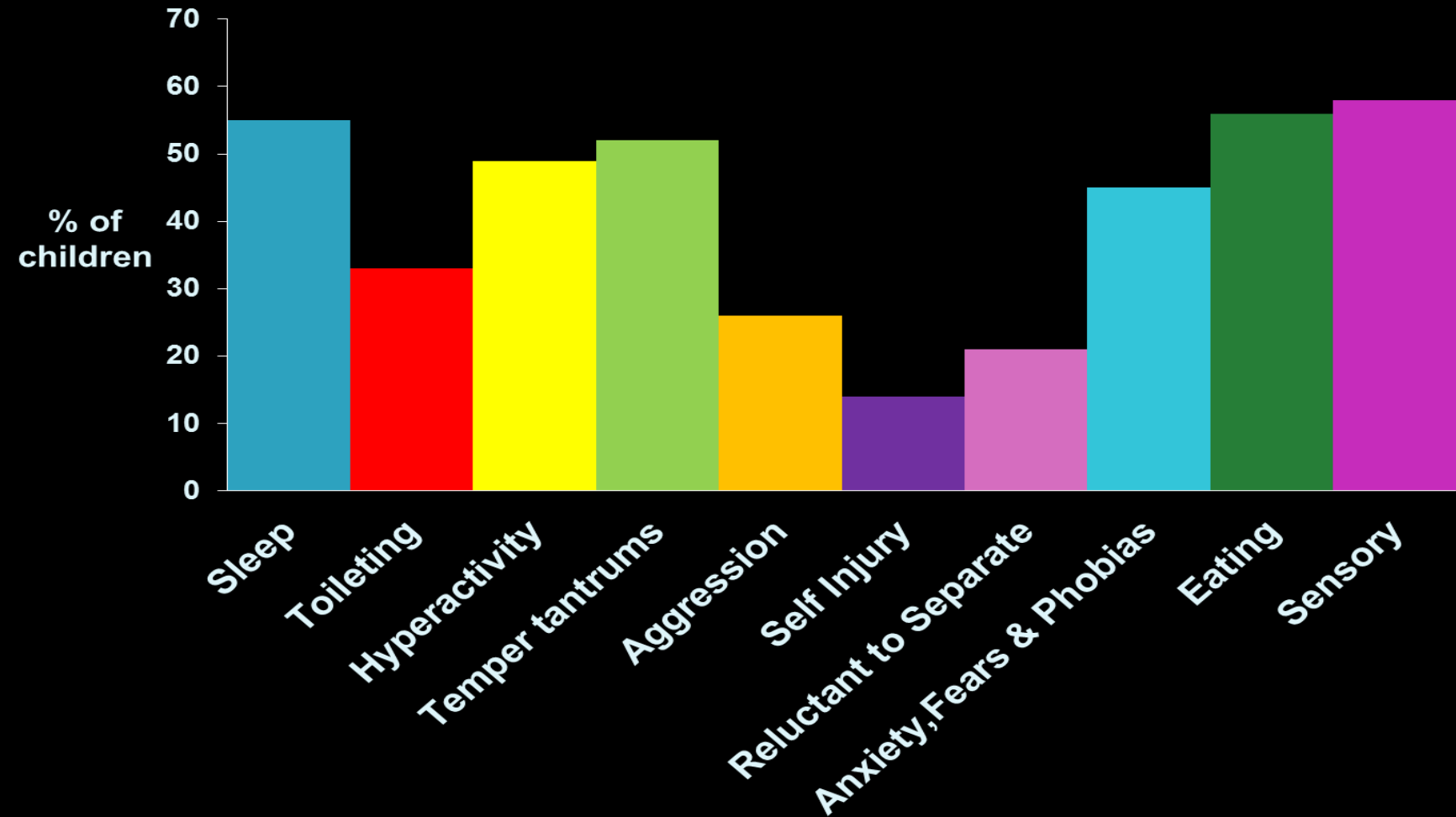
J Autism Dev Disord

DOI 10.1007/s10803-012-1622-9

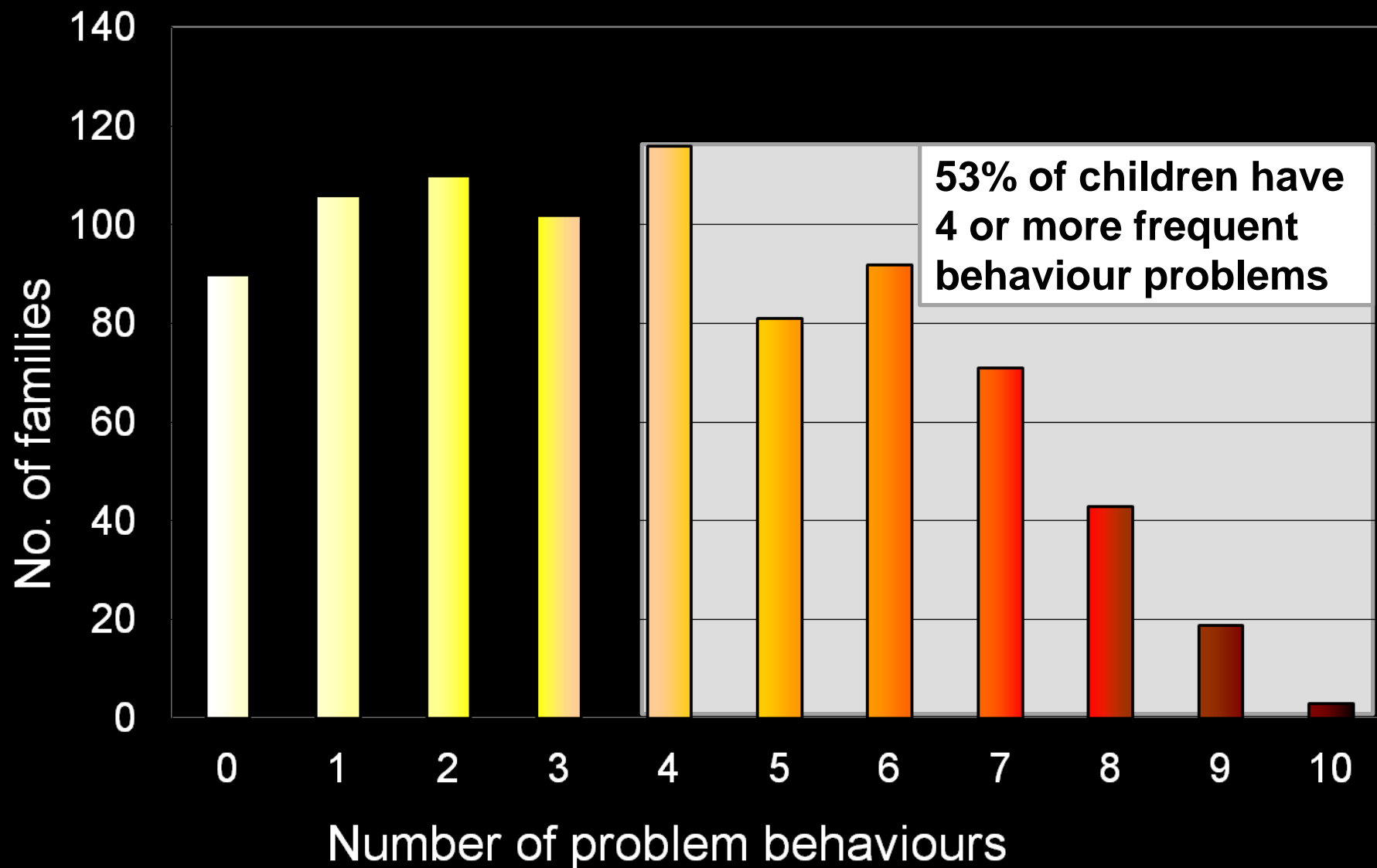
Morag Maskey · Frances Warnell · Jeremy R. Parr ·
Ann Le Couteur · Helen McConachie



Problem Behaviours: 3 times a week or more



Problem behaviours: 3 times a week or more



A young child with light brown hair is looking down at several yellow rubber ducks. The child is wearing a blue and white striped shirt. The background is a soft, out-of-focus indoor setting.

AUTISTICA

With knowledge comes understanding

One in a Hundred

Putting families at the heart of
autism research

Simon Wallace, Jeremy Parr & Alison Hardy



**To hear more about the
Adult Autism Spectrum
Cohort - UK, please
contact us by email:
adultautismspectrum@ncl.ac.uk
or telephone: 0191 282 1380**



Achievements (46 months)

3000 families can be contacted about research; data used for service development

Valid ASD diagnoses, representative of families of children with ASD in the UK; publication in revision; research data being published

Network of 70+ clinical teams work with us (engagement); additional teams want to recruit (capacity, scalability)

Refunded to 2017. Expansion 2015-2016; Trusts, Voluntary sector

New work with adults and relatives

Support to more than 40 research studies – current studies recruiting from Edinburgh, London, Oxford, Bristol, Belfast. Others....



Thank you

Questions?

www.asd-uk.com

asd-uk@ncl.ac.uk

Jeremy.Parr@ncl.ac.uk