



**OVERCOMING
BARRIERS.
ACHIEVING
POTENTIAL.**

Education for transformation

Caring for a child with autism across the life span: Issues, practice, and futures planning



Queen's University
Belfast

21st April 2017

ABIA Melbourne, Australia
Professor Karola Dillenburger
Centre for Behaviour Analysis

UNITED KINGDOM





"We'll Never Forget
This Day"

The New York Times.

FOR SALE: 10 CENTS
 THE NEW YORK TIMES
 PUBLISHED DAILY, EXCEPT ON SUNDAYS AND HOLIDAYS
 VOL. 40, NO. 10,000
 SATURDAY, APRIL 15, 1912
 NEW YORK, N. Y.

TITANIC SINKS FOUR HOURS AFTER HITTING ICEBERG; 866 RESCUED BY CARPATHIA, PROBABLY 1250 PERISH; ISMAY SAFE, MRS. ASTOR MAYBE, NOTED NAMES MISSING

Special Cable Telegrams
 to New York
 at 2:58 A. M.

RESCUED HERE TO SEE
 (Special Cable Telegrams)
 The Carpathia is on her way
 from New York to the
 Titanic.
 (Special Cable Telegrams)
 The Carpathia is on her way
 from New York to the
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 The Carpathia is on her way
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THE TITANIC
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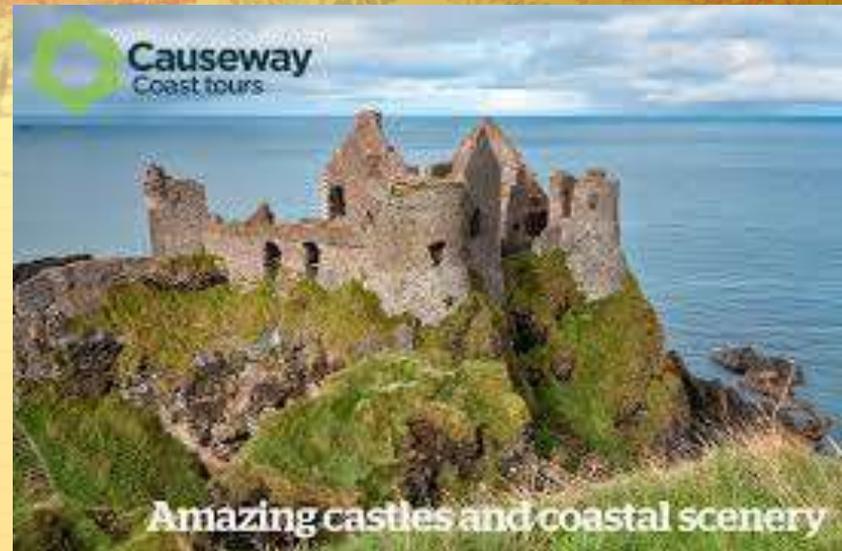
IS MAY SAFE
 (Special Cable Telegrams)
 Ismay is safe.
 (Special Cable Telegrams)
 Ismay is safe.

MRS. ASTOR MAYBE
 (Special Cable Telegrams)
 Mrs. Astor is maybe.
 (Special Cable Telegrams)
 Mrs. Astor is maybe.

NOTED NAMES MISSING
 (Special Cable Telegrams)
 The following names were
 noted as missing:
 (Special Cable Telegrams)
 The following names were
 noted as missing:

Special Cable Telegrams
 to New York
 at 2:58 A. M.







Centre for Behaviour analysis



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Outline



- ❖ Autism
- ❖ Caregiving across the lifespan
- ❖ Research findings
- ❖ Parent training

Caregiving across the lifespan



policy

training

care partnership

paid

Caring for younger generation, e.g., sons and daughters

Caring for peer group, e.g., spouse

Caring for older generation, e.g., parent

unpaid

technology

Self help

What is autism?

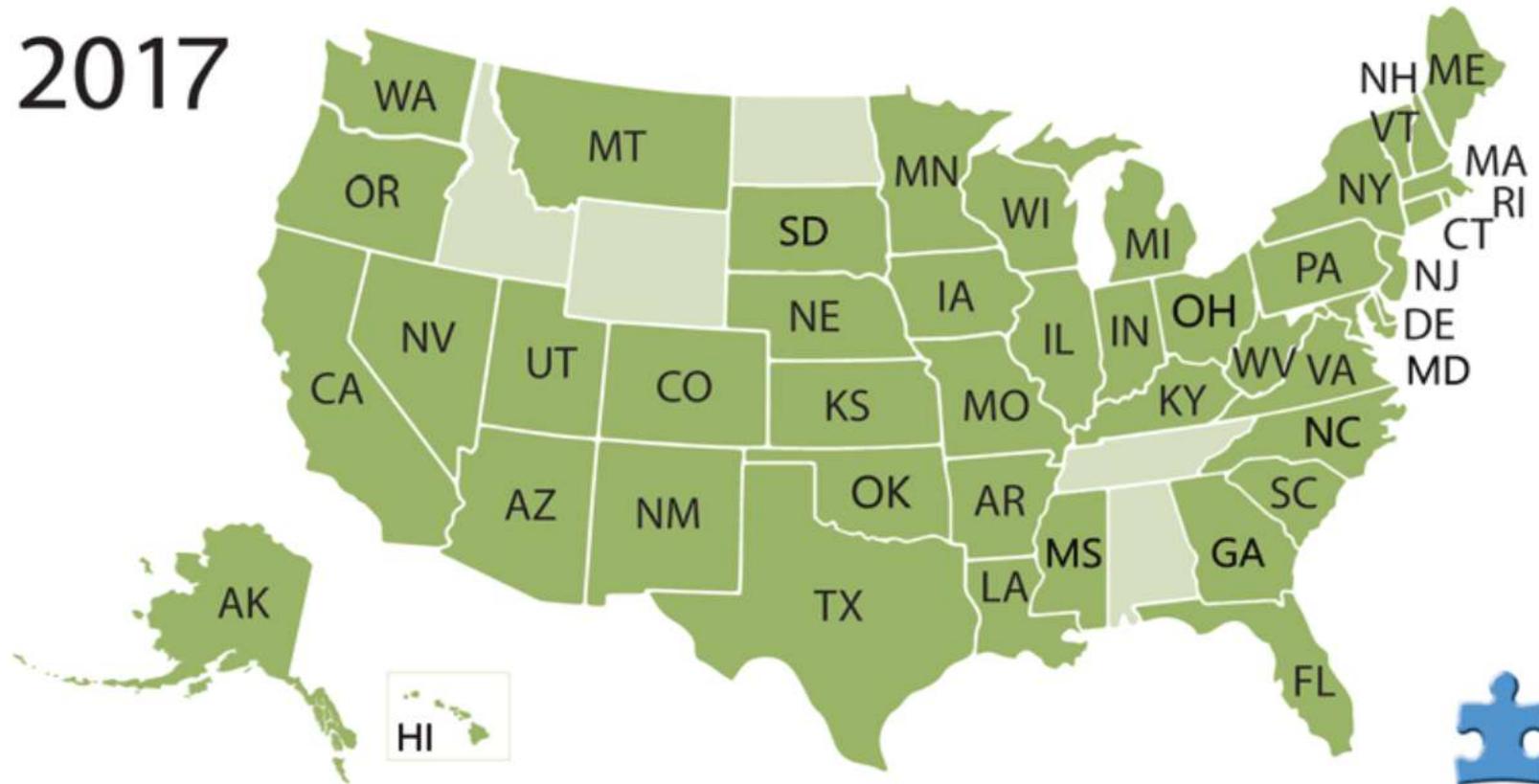


- Common features:
 - Pervasive difficulties in social communication
 - Restricted, repetitive behaviours
 - varying levels of functioning ('spectrum')
- Co-occurring Intellectual Disabilities (ID) (50-75%); epilepsy, mental health issues, gastro-intestinal
- Prevalence: 2.0-3.5% children

Caregiving: Early years



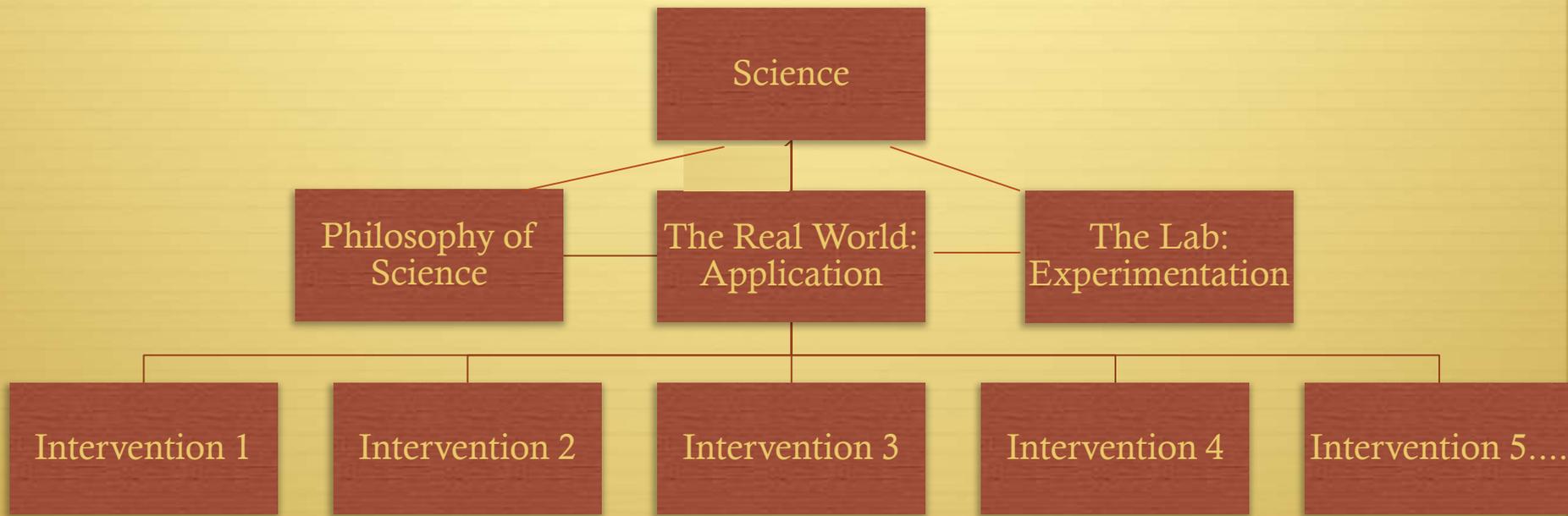
2017



These laws ensure parents can get access to ABA

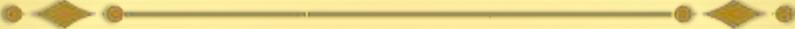
GREEN - States (45 + District of Columbia; US Virgin Islands) with enacted autism insurance reform laws

Why Behaviour Analysis?



Parents and professionals and policy makers decide:
Science or commercial package?

STAMPPP Project



- to develop and translate into European languages and cultures the
- *SIMPLE STEPS multimedia package*
- for parents of children diagnosed with ASD and professionals working with these families
- www.stamppp.com

STAMPPP: Science and the Treatment of Autism:
A Multimedia Pack for Parents and Professionals

Simple Steps

simplestepsautism.com

Automatic NCBI Welcome to NI...WiFi Service JEAB & JABA ...ch abstracts Save to Mendeley Facebook Apple AppliedBeha...sisMScPGDip iCloud Twitter Wikipedia Yah

Evisé Login... Evisé Login... (7) Facebook The whisky t... FTC Cracks... What the Ne... Maxstraße 2... Coping with...



Herzlich Willkommen, Karola Dillenburger! [Home](#) | [Ausloggen](#)

[Home](#) [Warum Simple Steps?](#) [Über Autismus](#) [Erfahrungsberichte](#) [kontaktieren Sie uns](#)

[Jetzt Kaufen](#)

[Meine Profil](#) [Anleitung](#) [Unterstützen](#) [ABA-Autismusprogramm](#) [Guide](#) [Ressourcenzentrum](#) [Glossar](#)



Die Online-Lernplattform für die Behandlung von Autismus

Wirksame Interventionen auf wissenschaftlicher Grundlage



Besonderheiten

Mitgliederbereich Merkmale:

- Video-Tutorials
- Benutzerhandbuch
- Glossar
- Ressourcenzentrum

Frei verfügbare Materialien für Sie!!

Laden Sie jetzt Teaching Resources.

Frei verfügbare Materialien für Sie. Klicken Sie für die Übersicht und weitere Informationen....

Für Eltern

Unterstützen Sie, wenn Sie es brauchen.

Simple Steps ist für Sie da. Klicken Sie hier für praktische, einfach anwendbare und kostengünstige Tools..

Für Profis

Unterstützung der Familie mit Interaktiven Ressourcen.

Klicken Sie hier für Informationen darüber, wie Sie können Familien in Ihrer Nähe helfen.

Simple Steps



"Judy's life, and ours has improved dramatically since beginning Simple Steps, I'd recommend it to anyone coping with Autism..."

Simple Steps Autism: Helping Children with Autism

A little about us...

Simple Steps Autism is an online tool offers teaching to help parents of children with autism. It is also a valuable teaching resource for students to understand how behavioural science may be applied to autism. It will help you understand autism and how it affects your child's ability to learn, to communicate and to build relationships. You can do something to help your child reach their full potential using our online video tutorials, animated lessons, advice sections, and downloadable resources.

To start your journey click here!



[More Testimonials](#)

[Purchase Now](#)

Join our online community:

Simple Steps Partners



Supported by the Creative Industries Innovation Fund



Fachhochschule Münster University of Applied Sciences



*This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

STAMPPP TEAM 2008-2010



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Germany
Spain
Norway

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copies

STAMPPP TEAM 2011-2013



Italy,
Netherlands
Iceland,
Sweden

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copies

Award winning

- International Dissemination of Behaviour Analysis Award
- Society for the Advancement of Behavior Analysis
- Association for Behavior Analysis-International Convention, San Antonio, TX. May 2015

International Dissemination of Behavior Analysis

The nominee for this award must be a person who, or organization that, has demonstrated a significant and sustained contribution to the international dissemination/development of behavior analysis outside of the United States.

Distinguished Service to Behavior Analysis
Scientific Translation
International Dissemination of Behavior Analysis
Effective Presentation of Behavior Analysis in the Mass Media
Enduring Programmatic Contributions in Behavior Analysis
International Publication

Previous winners:

Barry S. Parsonson and JaneMary Castelfranc-Allen (2014), SEEK Education, Inc. (2013), Andy Bondy (2012), Erik Arntzen (2011), Steven Hayes (2010), Joao Todorov (2009), Linda Hayes (2008), Eitan Eldar (2007), Joseph Morrow (2006), R. Douglas Greer (2005), Michael Davison (2004), Maria Malott (2003), Paolo Moderato (2002), Carolina Bori (2001), Liliana Mayo (2000), Comunidad los Horcones (1999), Emilio Ribes-Inesta (1998), Masaya Sato (1997), Murray Sidman (1996)

Danny Diamond



Isolated and ignored ... the autistic adults whose only support is elderly parents

By Kathryn Torney

ktorney@belfasttelegraph.co.uk

THERE is a huge gap between the level of need of people with autism in Northern Ireland and the support provided to them, it has been claimed.

Recent research carried out by the National Autistic Society Northern Ireland found that 70% of adults did not have enough support to meet their need and a massive 96% felt that with more support they would be less isolated.

It was also claimed that many adults with autism are ignored by local services and often rely on ageing parents for support.

The society's Ballymena Branch celebrated its first anniversary this week with a new local campaign to improve the lives of adults with autism.

The local branch was launched last year with help from a grant of £345,114 from the Big Lottery Fund's Reaching Communities programme to support families in the north-eastern and western areas of Northern Ireland.

It marked the anniversary on Tuesday with the launch locally of the I Exist campaign to raise awareness about autism.

Ann-Marie Martin, chair of the Ballymena Branch whose son has the condition, said: "This is the only survey of its kind and it reveals the huge gap between the level of need and the support available.

"The findings were the impetus behind our decision to celebrate

"Autism is a lifelong condition yet our research reveals that 55% of the Northern Ireland public who have heard of autism believe it mostly affects children. It also reveals that 90% of people do not know how common autism is. It affects an estimated 1 in 100 people.

"Another major issue is that local Health and Social Care Trusts do not know how many adults with autism there are in their

64%

The number of adults with autism who still live at home, according to an autistic society survey

local area, making it extremely difficult to plan and deliver services to meet their needs.

"The right support at the right time can make a huge difference, but many adults with autism are ignored by local services and often rely on ageing parents for support. In our survey 64% of adults with autism still live at home.

"Many adults with autism face a lack of recognition and understanding, a lack of suitable services and a lack of support, all of which have a devastating impact on adults and their families."

Robin Devlin, who lives with

life skills such as cooking, ironing and washing clothes. I still struggle with these.

"I would say I'm not alone on that boat. From both insight and experience my opinion is that people with Asperger's need all the help and support they can get.

"Autism awareness needs a serious boost in Northern Ireland and I hope the I Exist campaign will provide that."

Another parent of an adult with autism said: "My son is socially and economically isolated - he gets no support from his local health service whatsoever. I am his principal carer and I get no support either."

The Ballymena Branch, which currently services nearly 40 families in the Ballymena area, was established at the beginning of 2008 by two local parents of children with autism, helped by the family support worker from the National Autistic Society (NAS).

NAS Northern Ireland coordinator Regina Cox said I Exist represents a message from adults with autism who want to be recognised and deserve to have their needs understood and fulfilled.

"We are calling on the Northern Ireland Assembly to think, act, and transform lives," she said.

Breidge Gadd, Big Lottery Fund NI Chair, said: "The Reaching Communities programme is a very important part of our work in Northern Ireland, ensuring that lottery cash reaches strong projects led by the voluntary and commu-

Settled leg



A 13-year battle over a chocolate teacake was finally settled in highest court in the land yesterday

Marks & Spencer took action against the taxman, who charged VAT on its popular chocolate teacakes between 1973 and 1994, successfully claiming that they should have been zero-rated biscuits.

In 1995, the high street chain claimed a repayment of £3.5 million from the Customs and Excise Commissioners who refused to refund VAT on the teacakes.

Parenting a adult with autism: Chris



Benchmarking Autism Services Efficacy: BASE Project



- Need for more research on long-term caregiving
- Three year project funded by OFMDFM
- Aim: Helping the most vulnerable out of the poverty trap and reducing inequality
- Policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities
- Four Phases

BASE Project: Literature review



- Review of peer-reviewed research focusing on autism, Intellectual Disability and poverty, education and employment
- Policies, strategies and reports from Government Departments, educational institutions, and disability organisations since *Taskgroup on Autism report* in 2002.

Key findings



- 2.3% of NI school children have autism
- 200 new referrals/month = 100 diagnosis/month
- 100 on waiting list/not diagnosed;
- 3000+ on waitlist for diagnosis
- ABA-based interventions not widely available in Europe.

BASE Project: Attitude survey



- **Northern Ireland Life and Times (NILT) Survey 2012**
“Autism module” (18+ys; n=1204)
- **Kids Life and Times (KLT) Survey (11 ys; n=2319)**
- **Young Life and Times (YLT) Survey (16 ys; n=1034)**

Key findings



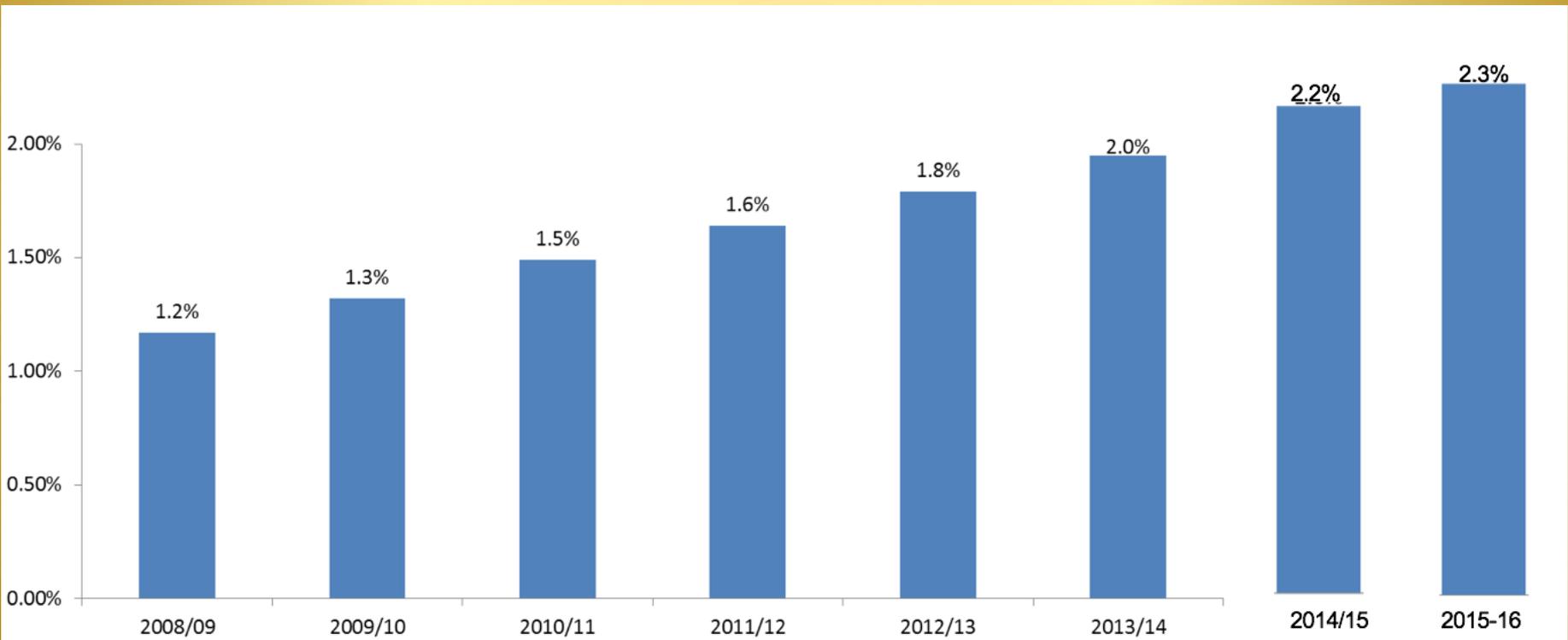
	11 year-olds N=2319	16 year-olds N=1034	Adults (18+) N=1204
Autism awareness	50%	80%	82%
Know someone with autism	43%	72%	51%
Have autism	2.7%	3.1%	0.1%
Knowledge about autism	Good	Good	Good

BASE Project: Secondary data analysis



- Secondary data analysis of all existing relevant and available data sets
- Focused on disability and poverty, employment, education, quality of life, and economic impact of policy.

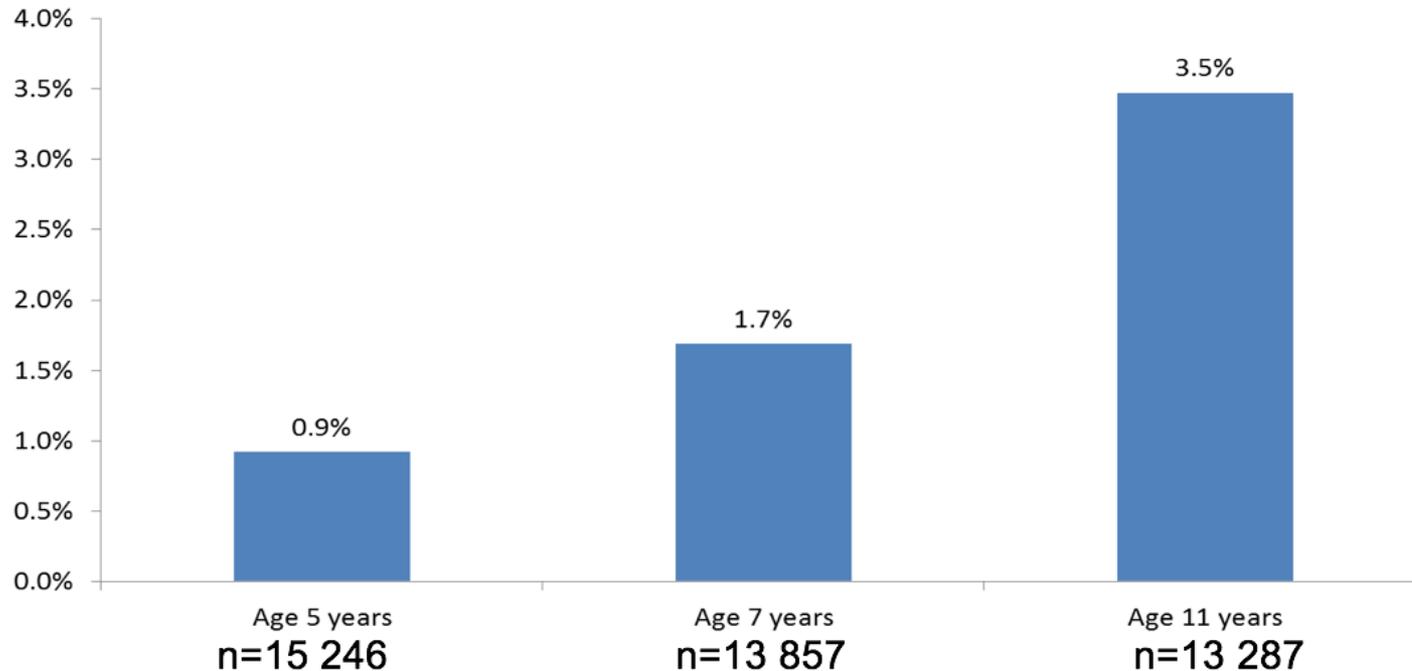
Key findings



2.3% of NI school children have autism in 2016 (School census)

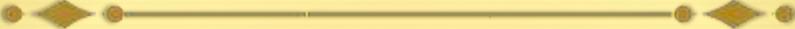
Key findings

Autism in Millennium Cohort Study (UK); n=18,522 children born in 2000



In UK, 3.5% of 11 year-old children are thought to have autism

Key findings



- Children with autism miss school more (up to 13 days more) than other children
- Frequently excluded (20%), and bullied (20%)
- Educational attainment is 20-40 percentage points lower than other children
- Only 6-15% adults with autism are in employments

Key findings



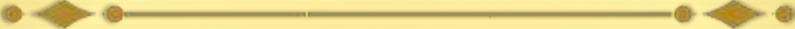
- Unemployment high in families affected by autism (approx. x5);
- Parents give up employment/reduce hours of work
- Income lower in families with autism; 7 percentage points lower than other families
- Families with autism are likely to live in deprived areas; 6 percentage points higher than other families

BASE Project: Qualitative data



- Focus groups, interviews, and questionnaires with stakeholders
- 798 professionals and 41 service users
- Included individuals with autism, caregivers, employers, educators, health and social care staff, and policy makers

Key findings



- Autism diagnosis protracted (often >2 years)
- ‘Early intervention’ is brief and patchy (e.g., one 1-hour visit; leaflets)
- Early Intensive Behaviour Analysis-based Interventions (evidenced as effective) are not available in statutory sector
- Referred to voluntary sector (e.g., www.peatni.org)

Key findings



- Pre-qualifying: no or very little autism training (<1-2 hours)
- In-service autism training: generally very basic (<1-2 hours)
- Not availing of University autism training (MScASD or MScABA)
- Confirming studies of self-reported knowledge

Cost for families



- Estimated cost of autism/lifetime £0.9-1.5 mill. in UK
- Total annual cost of autism £34 billion in the UK:
 - of this £29 billion for adult care
 - very little investment in early intervention in UK
 - the opposite is true for USA
- Cost of bringing up a child with autism
approx. x3-6 greater than for other children

Ageing caregivers



What the future holds: Older people caring for adult sons and daughters with disabilities

Karola Dillenburger & Lyn McKerr
School of Education
Queen's University Belfast



Report for the Changing Ageing Partnership (Cap)
Institute of Governance, School of Law, Queen's University Belfast.

older louder stronger

Background

In Northern Ireland there are 185,000 unpaid carers.
25% providing more than 50 hours of care per week.
Almost 39,000 are aged 60+.

89% of adults with learning disabilities live in the
community



20% of adults with learning disabilities live with
parent aged 70+.

Unpaid carers save UK more than £87 billion,
exceeds total NHS expenditure.



Method

Participants:

29 older carers of 27 sons/daughters with disabilities.

Tools:

Semi-structured interviews took 45-60 min.

General Health Questionnaire (GHQ-12).

Analysis:

Interpretative Phenomenological Analysis (IPA)



Main findings

38% of the carers were over 65 years old (range 47-84 years).

Average age of sons and daughters with disabilities was 33.48 years.

Caring was a full-time job for 90% of the participants and included physical care in 86% of the cases.

Concern about psychological health of carers was twice that of the general population (35% vs 17%).





Parents' voice

“The thing is, as we get older you do think what if something happens to us, what will happen to ‘Billy’ ...

My daughter says ‘Don’t worry Mummy I’ll look after ‘Billy’’, but I don’t want her to. I don’t want her to have that life that I had, and then again, I really don’t want him in a home, so I just hope, I hope that God will take him before he takes us, but that’s not always the way, so you have to think of these things.”

Main findings

79% enjoy spending time with their sons and daughters.

86% greatest challenges: lack of respite, difficult behaviours, and meeting social needs.

69% received support from family, 31% did not have any family support.

14% received help from friends or neighbours.





Parents' voice

“You see when ‘Johnny’ was given to us, he was given to us as a normal child, then a year later I’m sitting in an office with a paediatrician and he’s telling me we’ll look after him ‘til he’s 5, if he survives that.

So, I mean, he’s 40 years old now and 40 years is an awful long time!”



Main findings



79% had no care plan, although care arrangements had changed for 69%.

66% discussed necessary changes with social services.



36% did not receive help or had to fight for help.

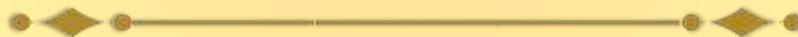
76% stated that their own health was good or fair, despite suffering from various health problems.



© Crown Copyright

Parents' voice

“Well, I don’t dwell on it... We have carers coming in every day, three times a day, it’s an intrusion in your life.



If you have your dinner at a certain time... you’re eating after 8 o’clock, or you’re eating earlier when you don’t really want to, but we can’t get rid of the carers because there might come a time when we can’t change ‘Sean’, if we have to and the carers aren’t here...”

Main findings

67% relied on informal family arrangements in case the main carer fell ill.

48% had no adequate substitute care arrangements.

72% had not considered making long-term plans for the future care of their sons or daughters with disabilities.





Parents' voice

“Our own kids were always reared to think of family first... that sounds great when you're rearing them and you know they're all at home... but I've begun to think this over...

the last 20 years really... you're also putting pressure on them, you may not realise at the time, pressure for looking after 'James'. That's not what you meant to do but you wind up because you have... those values are there, the family look after each other...”



Parents' voice

“Our biggest problem, as far as both ‘Jenny’ and ‘Gerry’ are concerned, is how long are we able to go on?”



We think a lot about that... and we haven't come up with an answer. Because, our health could change, overnight.”



Making sense

Traditional Psychology:
Age determines behaviour.

Behaviour analysis:
Context and circumstances affect
behaviour.

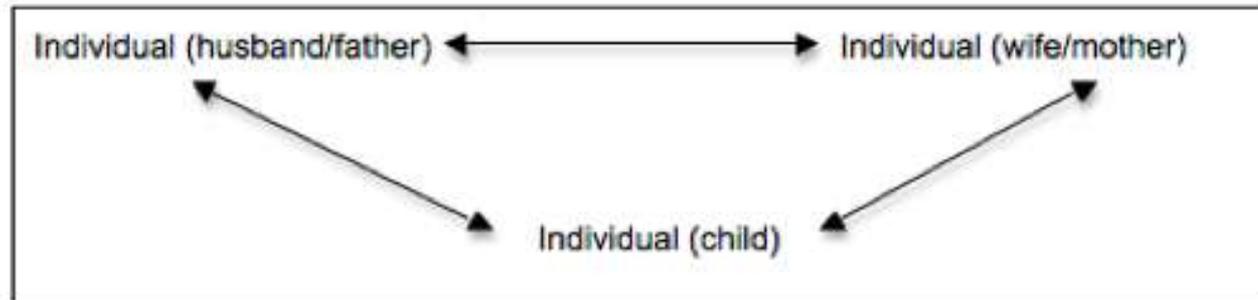


Figure 3: Illustration of family relationships

Reciprocal relationships between individual/husband and individual/wife



Reciprocal relationships between father, mother, and child



Network of reciprocal relationships between father, mother, and child

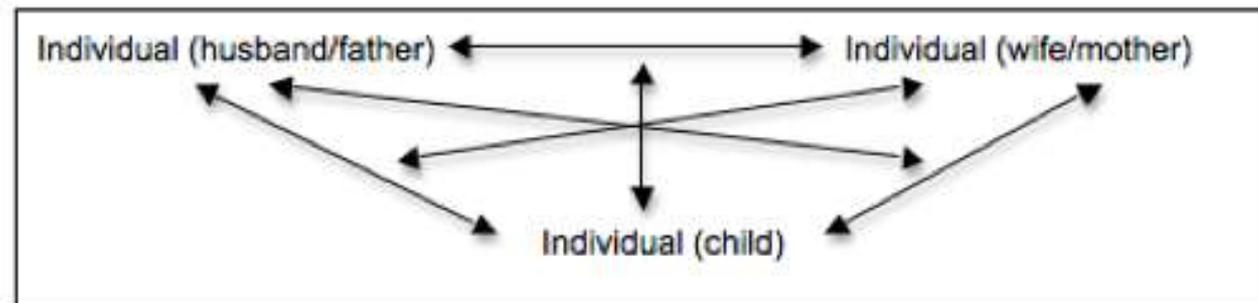




Figure 4: Illustration of lack of relationships when parents pass away

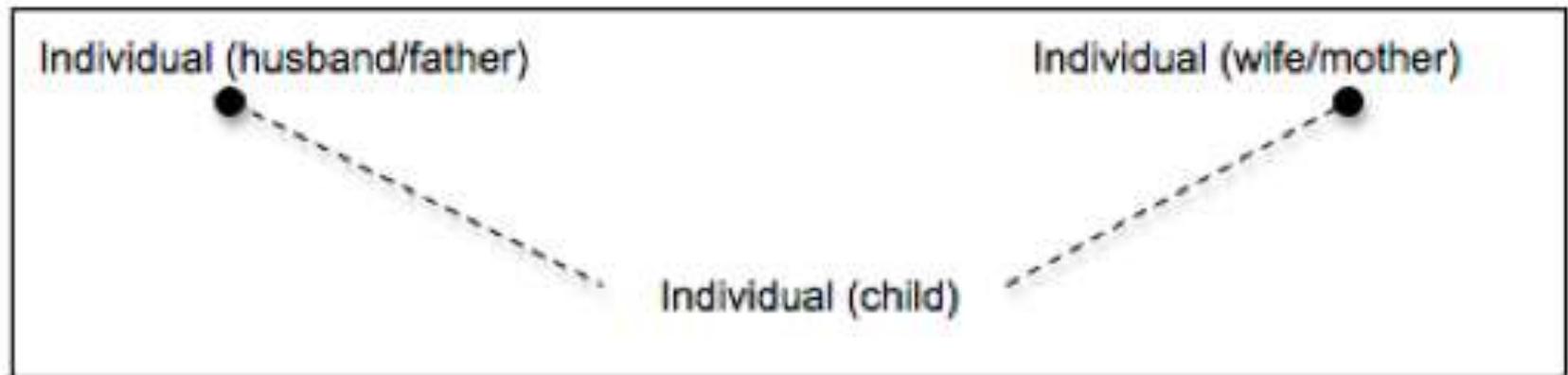


Figure 5: Illustration of necessary support network

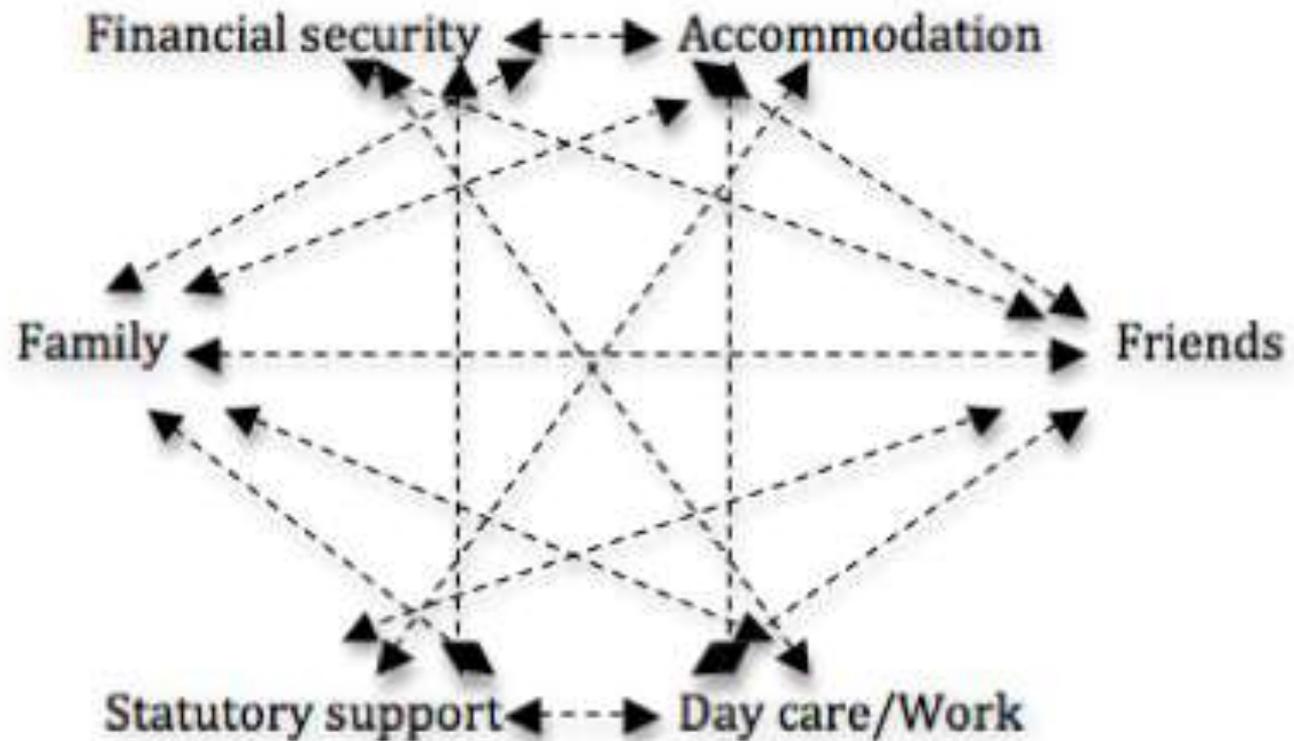
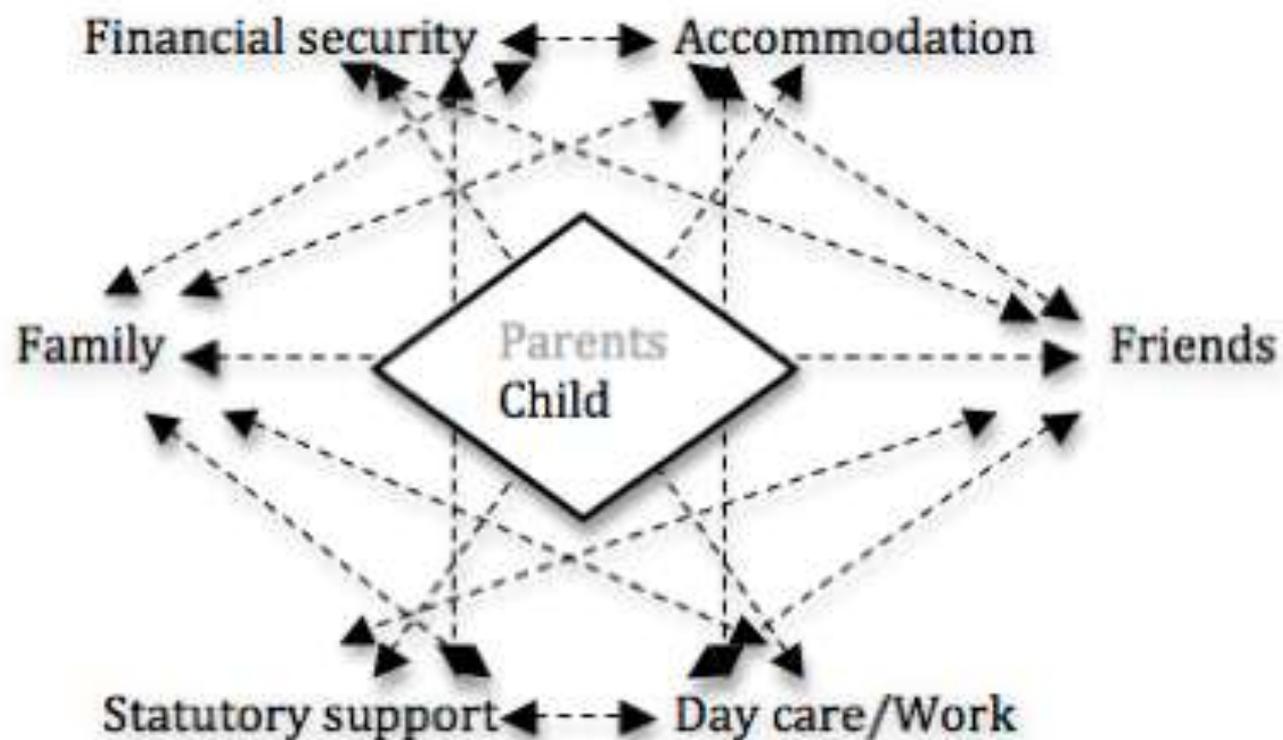


Figure 6: Illustration of parents/child at the centre of network of support



Recommendations



- Evidence-based early interventions in place to enhance life skills and choices.
- An advocate available to each family throughout the life span, to help set up and coordinate appropriate networks of support well in advance.
- Suitable alternative accommodation available for adults with all levels of additional individual need.



Recommendations

- Support services should be easily accessible, especially in rural areas.
- Education and training for service providers needs to focus on evidence-based best practice to meet the needs of these families.



Recommendations



- ‘Lifespan’ approach (from early diagnosis, early behaviour analysis-based interventions, to active adulthood and beyond)
- Integrated working between Departments
- Relevance to Disability-, Anti-Poverty-, Employment-, Housing- and Health- Policies and Strategies

Recommendations



- Discontinue watch-and-wait approach; introduce triage system for diagnostic determination (DHSSPS);
- Conduct cost-savings analysis of autism diagnosis to decide (1) to internally resource diagnostic teams **or** (2) outsource autism diagnosis
- Employer and employee training in autism

Recommendations



- Monitor attendance, attainment and pastoral care of children with autism in schools
- Ensure teacher/staff training in autism to high levels of international best practice
- Monitor employment rates in families affected by autism
- Ensure recommendations are in place to allow parents/caregivers remain/return to paid employment

Scales of equality

Inequality

Towards
equality

High cost of autism
Late diagnosis

Lack of staff training

Lack of early intervention
School exclusion

Unemployment

Good public awareness

Post- secondary Education

Scales of poverty and equality

Inequality

Towards
equality

Autism awareness
Staff training

Early diagnosis
Early intervention

School inclusion
Post-secondary

Employment
Housing

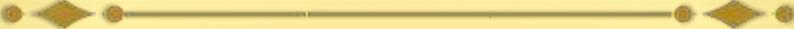
Chris goes to college



Chris Goes to Collégé

Jon Anderson
Maria Anderson
and Chris Davis

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