



Knowledge Exchange Seminar Series (KESS)

...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland



Preventing poverty and social exclusion for those affected by autism and their families

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Outline

- What is autism
- How does autism increase vulnerability to poverty and exclusion
- The 4 phases of the BASE project
 - Benchmarking Autism Services Efficacy
- Recommendations: Out of the poverty trap and reducing inequality



What is autism?

Autism Spectrum Disorder (DSM-5; ICD-10)

- Pervasive difficulties in social communication
- Restricted, repetitive behaviours
- Varying levels of support needs

Common co-occurring conditions

- Intellectual Disabilities (ID) (50-75%);
- Mental health issues,
- Physical health issues e.g., epilepsy, gastro-intestinal

Estimated prevalence across all age ranges:

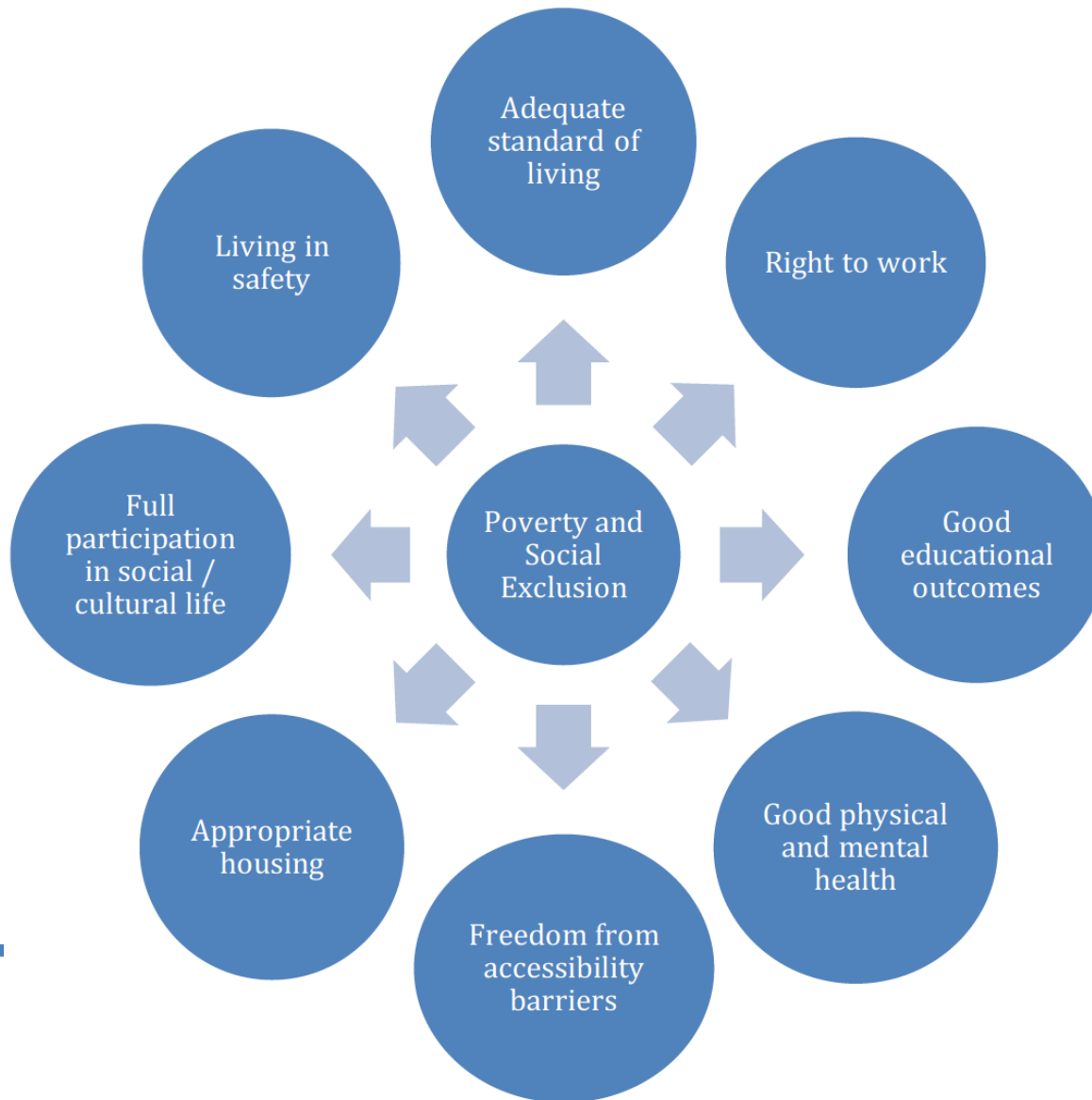
- 1 in 68 (CDC, 2014).
- 2.3% of children in NI (DHSSPS, 2016)

How does autism increase vulnerability to poverty and exclusion?



<https://www.youtube.com/watch?v=O0vCz2KWMM0>

UNCRCRPD: Rights for individuals with disabilities, including autism.



BASE Phase 1:

Literature review

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



BASE Phase 2: NILT Autism Module

- Northern Ireland Life and Times (NILT) Survey in collaboration with ARK (QUB & UU)
- Quantitative baseline data on awareness, knowledge, attitudes, and behaviours among the general public (n=1204)



BASE Phase 3:

Secondary data analysis

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



BASE Phase 4:

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.



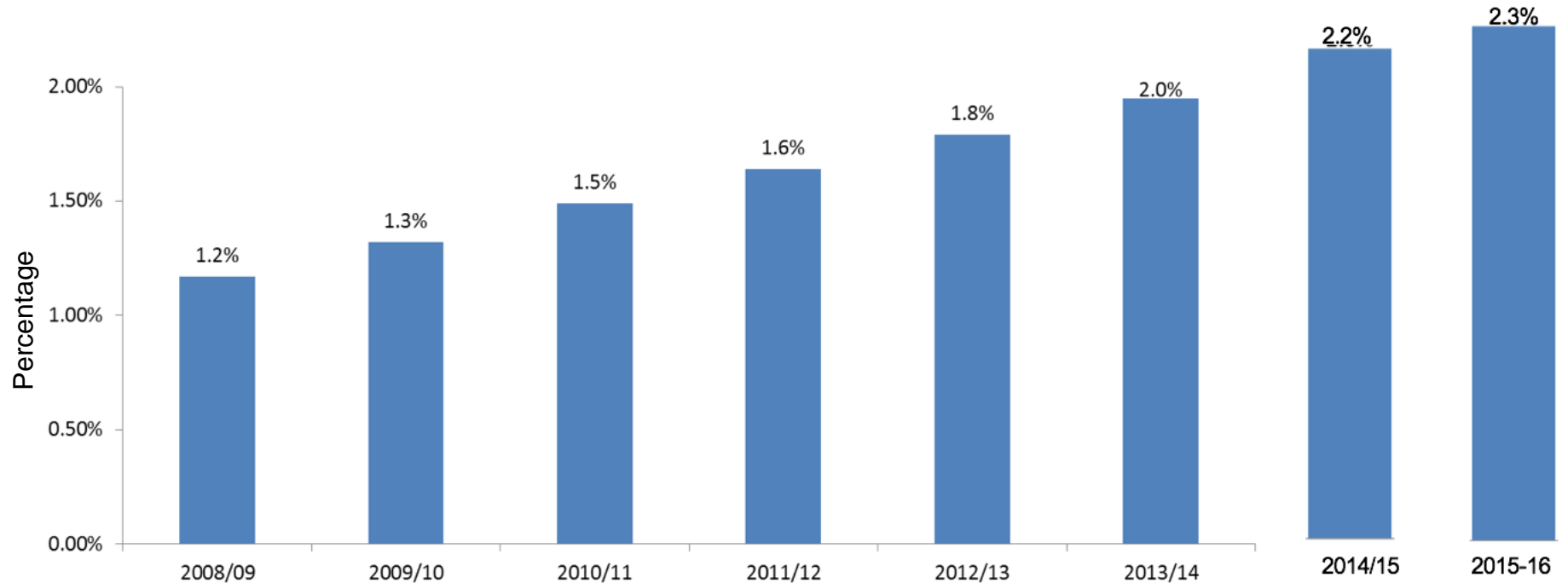
Key findings:

Diagnosis and SEN Assessment

- Approx. 200 new referrals per month in NI
 - 100 new diagnoses per month;
 - 100 new on waiting list or not diagnosed.
- Over 3000 children on waiting list for diagnosis
- Delay in diagnosis; over 2 years
- 59% of SEN Statements take longer than 26 weeks
- Majority of children with autism assessed to be at Stage 5 of the Special Educational Needs assessment



Key findings: Rising autism prevalence in NI Schools



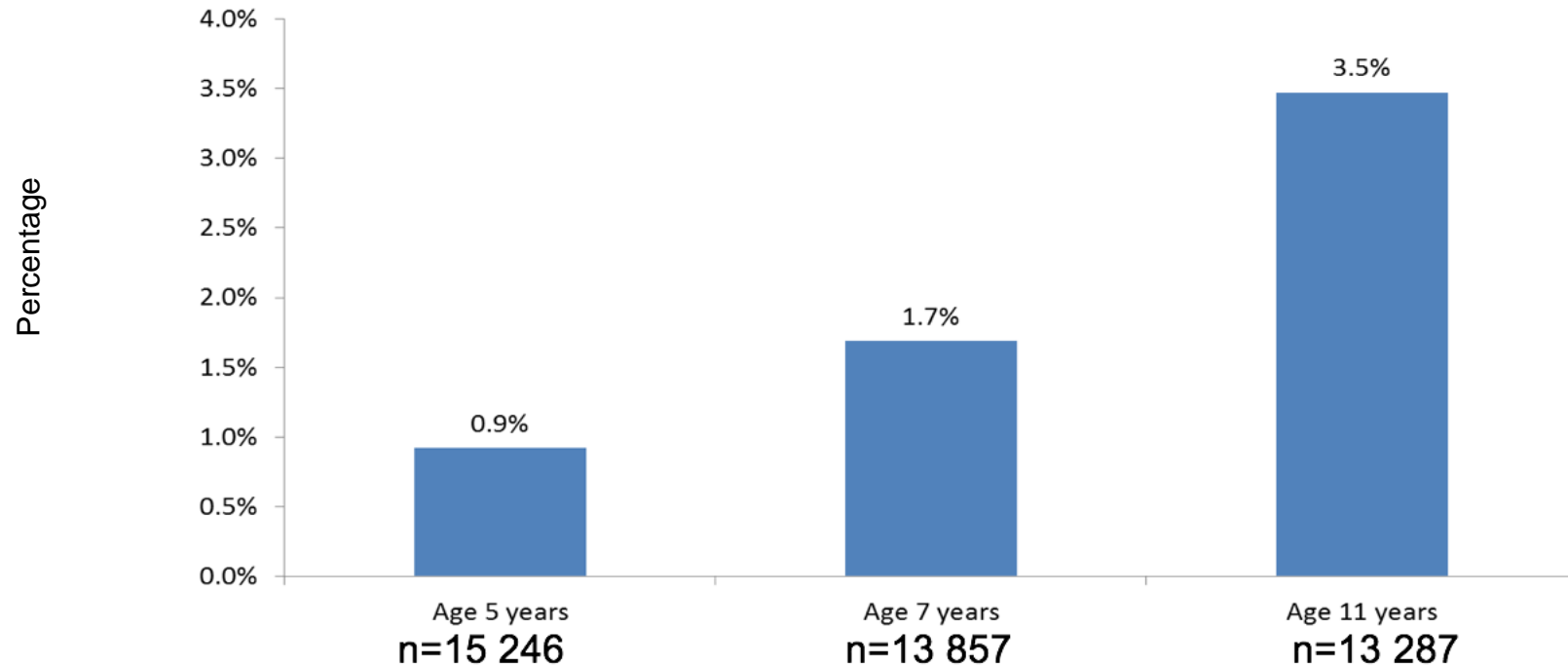
2.3% of NI school children have autism in 2016 (School census)



Key findings:

Rising autism prevalence in NI Schools

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:

Autism awareness/attitude surveys

	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
Attitudes towards autism	Positive	Positive	Positive



Key findings:

Staff Autism Training

- In-service staff training in autism is generally very basic; mostly Level 1 (1-2 hours); only few staff have Level 3 (1-2 days).
- Local University autism training is not included in Autism Strategy/Action Plan!
- Local Universities offer
 - MSc Autism Spectrum Disorder (QUB);
 - MSc Applied Behaviour Analysis (QUB and UU);
 - Pre-and Undergraduate level courses/modules (QUB; UU; OU).



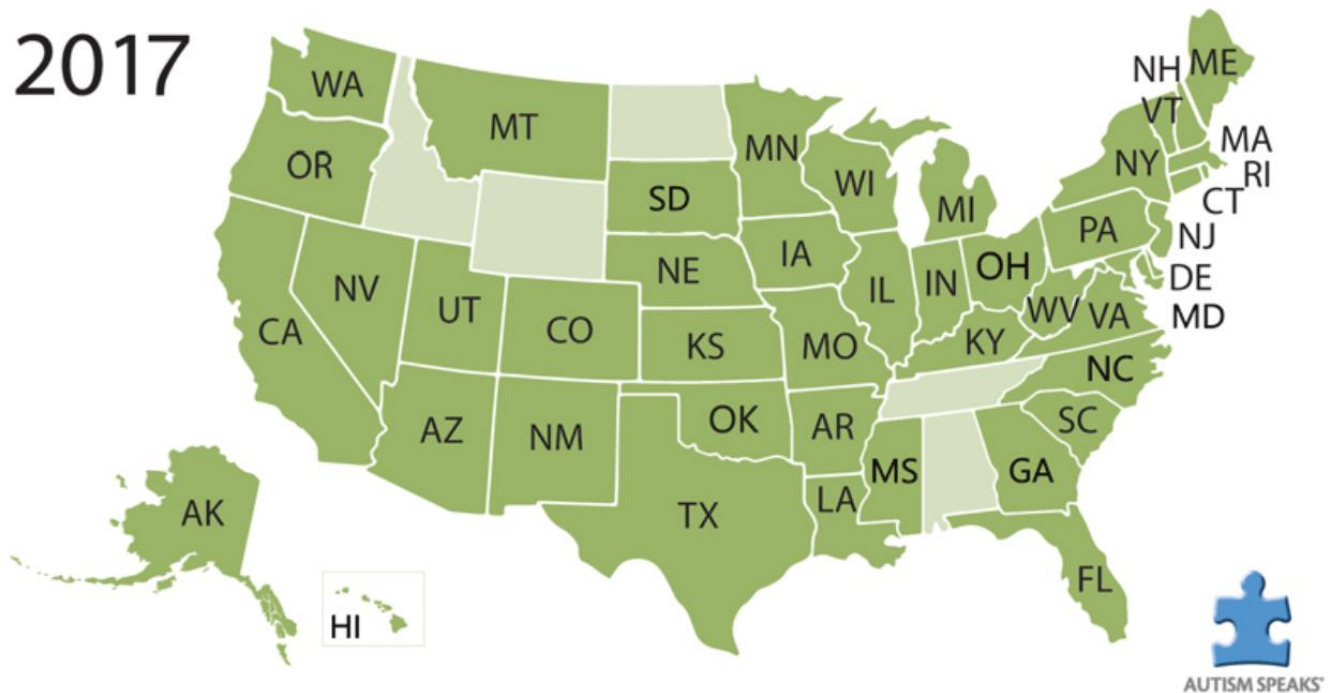
Key findings:

Poverty and inequality

- Estimated cost of autism/lifetime £0.9-1.5 million
- Total annual cost of autism is £34 billion in the UK;
- Cost for care for adults much greater (£29 billion) than for children £5billion
- The opposite is true for USA; more investment in early evidence-based intervention
- Cost of bringing up a child with autism in UK is approx. 3-6 x greater than for other children



Key findings: Evidence-based interventions



Laws to ensure funding for ABA-based early intervention in USA

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

Key findings:

Evidence-based interventions

In Northern Ireland

- ‘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
- Parents have to rely on small voluntary organisation, that does not receive Government funding



Key findings: Education outcomes

Children with autism:

- Miss school more than other children (up to 13 days more per year; can be total of nearly 5 weeks),
- Are frequently excluded (20%), and bullied (20%)
- Have lower educational attainment than other children (20-40 percentage points lower)



Key findings:

Unemployment and deprivation

- Adults with autism have low employment rates (6-15%)
- Exact unemployment figures not known in NI
- Unemployment is high in families of individuals with autism (approx. x5)
- Many parents give up employment/reduce hours of work
- Income is lower in families with autism than in other families (7 percentage points lower)
- Families with autism are likely to live in deprived areas than other families (6 percentage points higher)

Scales of poverty and inequality

Poverty and
inequality

Out of poverty
and 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

Key recommendations:

Autism awareness

Autism awareness in Northern Ireland

- High amongst adults, teenagers and children
- General awareness campaigns are working
 - Light up Blue (LUB) by Autism Speaks, e.g., Belfast City Hall (2014)
 - 2nd April World Autism Awareness Day (WAAD); United Nations (2007)
 - Understanding autism courses, by statutory and voluntary bodies
- More general autism awareness raising is not needed, e.g., no TV advertising campaign
- Specialist autism awareness training for frontline medical and justice staff



Key recommendations:

Staff training and research

- Commission cost-savings analysis for autism training
- Actively engage with HE sector in autism training
- Actively engage with HE sector in autism research



Key recommendations: Diagnosis and assessment

- Discontinue watch-and-wait approach
- Introduce triage system for diagnostic determination
- Conduct cost-savings analysis of autism diagnosis to decide
 - (1) to internally resource diagnostic teams or
 - (2) outsource autism diagnosis

Key recommendations:

Early intervention

- Conduct cost-saving analysis of early intensive behaviour analysis-based interventions
- Decide if early intensive behaviour analysis-based interventions
 - (1) be made available in statutory sector **or**
 - (2) outsourced
- Ensure staff training of international best practice interventions is available
- Develop a 'signature project' for early intensive ABA-based interventions



Key recommendations:

Education

- 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



Key recommendations:

Further and Higher Education and Training

- Monitor attendance, attainment/completion, and pastoral care of young people and adults with autism in FE and HE
- Ensure FE/HE staff training in autism, where appropriate



Key recommendations:

Employment

- Monitor employment rates, attainments, and pastoral care of adults with autism
- Ensure employer and employee training in autism



Key recommendations:

Employment for families

- Monitor employment rates in families affected by autism
- Ensure recommendations 1-7 are in place to allow parents/caregivers remain/return to paid employment



Key recommendations:

Housing and futures planning

- ‘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



Key recommendations

Poverty and
inequality

Out of poverty
and towards
equality

Autism awareness
Staff training

Early diagnosis
Early intervention

School inclusion
Post-secondary

Employment
Housing



Northern Ireland
Assembly



Queen's University
Belfast



The Open
University



Ulster
University

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