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
UNCRPD: Rights for individuals with disabilities, including autism.

- Adequate standard of living
- Right to work
- Good educational outcomes
- Good physical and mental health
- Freedom from accessibility barriers
- Appropriate housing
- Full participation in social / cultural life
- Living in safety
- Poverty and Social Exclusion
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

<table>
<thead>
<tr>
<th></th>
<th>11 year-olds (N=2319)</th>
<th>16 year-olds (N=1034)</th>
<th>Adults (18+) (N=1204)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism awareness</td>
<td>50%</td>
<td>80%</td>
<td>82%</td>
</tr>
<tr>
<td>Know someone with autism</td>
<td>43%</td>
<td>72%</td>
<td>51%</td>
</tr>
<tr>
<td>Have autism</td>
<td>2.7%</td>
<td>3.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Knowledge about autism</td>
<td>Good</td>
<td>Good</td>
<td>Good</td>
</tr>
<tr>
<td>Attitudes towards autism</td>
<td>Positive</td>
<td>Positive</td>
<td>Positive</td>
</tr>
</tbody>
</table>
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 £5 billion
- 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
  - High cost of autism
  - Late diagnosis
  - Lack of staff training
  - Lack of early intervention
  - School exclusion
  - Unemployment

- Out of poverty and towards equality
  - Good public awareness
  - Post-secondary Education
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)
  - 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
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.