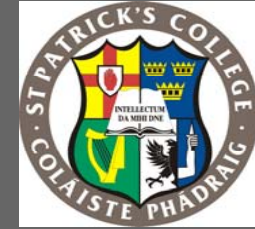


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# International review of the literature of evidence of best practice provision in the education of persons with Autistic Spectrum Disorders

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with

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# Overview

- Background to review
- Context of review
- Method
- Main findings
- Conclusions
- Recommendations and implications for research and practice
- Discussion

# About the presenters: Sarah

**Sarah Parsons** (BSc. (Hons) Psychology; PhD) is a Senior Research Fellow in the School of Education, University of Birmingham. She has significant research experience in disability related projects and has particular interests in the use of innovative technologies for children with autism and the views and experiences of disabled children and their families.

## **Selected publications include:**

Parsons, S., Lewis, A., & Ellins, J. (2009). **The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey.** *European Journal of Special Needs Education*, 24 (1), 37-58.

Parsons, S., Daniels, H., Porter, J. & Robertson, C. (2008). **Resources, staff beliefs and organisational culture: first- and second-order factors in the use and implementation of ICT for adults with intellectual disabilities.** *Journal of Applied Research in Intellectual Disabilities*, 21, 19-33.

Parsons, S., Mitchell, P., & Leonard, A. (2004). **The use and understanding of virtual environments by adolescents with autistic spectrum disorders.** *Journal of Autism and Developmental Disorders*. 34(4), 449-466.

# About the presenters: Karen

**Karen Guldberg** (BA (Joint Honours); PGCE; PGCert; MA; M.Ed; PhD) is a Lecturer in Autism Studies, School of Education, University of Birmingham. Karen taught children with autism for many years and now delivers training programmes for practitioners. Her research focuses on educational intervention for children with autism and the training needs of practitioners.

## **Selected publications include:**

- Guldberg, K. (2008) **Adult learners and professional development: Peer to peer student learning in a networked community.** *International Journal of Lifelong Education*, 29 (1): 35-49.
- Pilkington, R. and Guldberg, K. (2008) **Conditions for productive networked learning among professionals and carers: The WebAutism Case Study,** In Dirckinck-Holmfeld, L., Jones, C. and Lindstrom, B. *Analysing Networked Learning Practices in Higher Education and Continuing Professional Development*, pp. 43-63, Sense publishers.
- Guldberg, K. & Pilkington, R. (2007) **Tutor roles in facilitating reflection on practice through online discussion,** *Journal of Educational Technology and Society*, 10 (1), 61-72.

# Background

- Report of the Task Force on Autism (DES, 2001) – wide ranging review of provision and available evidence for young people with ASD
  - 108 submissions from parents, service providers and others
  - Review of research literature and interventions
  - Review of existing educational provision (RoI, NI and England)
- 179 recommendations relating to policy and practice across all aspects of provision

# Current review

- Commissioned June 2008
- Aims:
  - to review best practice in educational provision for persons with ASD that demonstrate *best outcomes for the person*
  - update the evidence base published since the Report of the Task Force on Autism (DES, 2001)
  - make recommendations for best provision for children and young people (CYP) with ASD
- Review carried out June – Nov 2008

# Statistics - prevalence

- CYP with ASD → prevalence rate of 0.56% (Task Force Report)
- This figure + expert estimates + census data 2002 → 6,026 CYP with ASD aged 0-18 years (Implementation Report; NCSE, 2006)
- Very similar to MRC estimated prevalence (2001)
- Numbers of CYP diagnosed rising internationally
- Expertise and experience in different areas influences rates

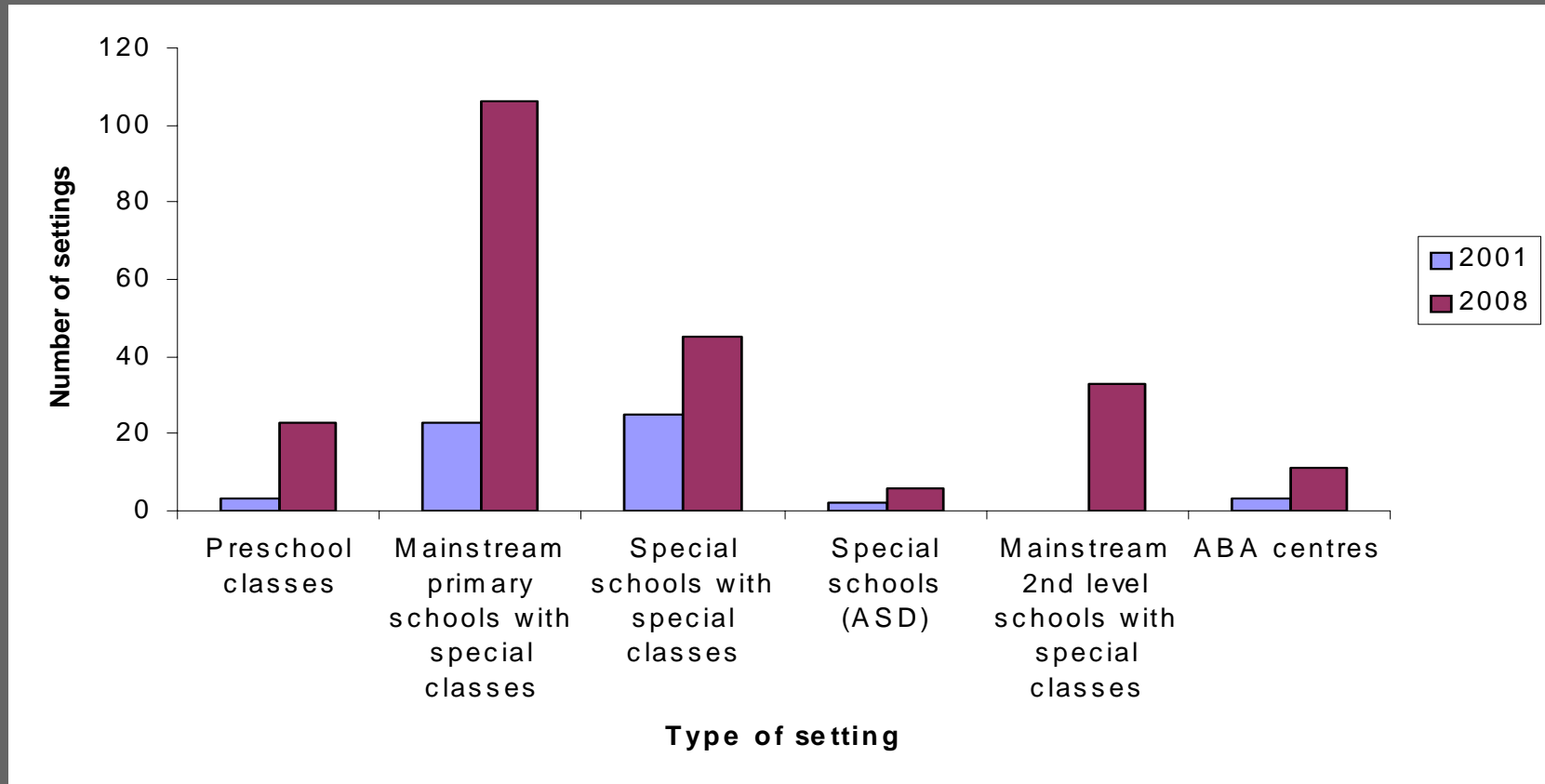
# Policy & context

- Current policy for SEN → continuum of support and provision
- Range of provision to meet varying needs
- Majority of children on the autism spectrum educated in non-autism-specific provision
- Notable increase in recent years in autism-specific-provision:
  - Special classes in special and mainstream schools
  - Autism-specific schools
  - Home Tuition
  - ABA centres (pilot scheme: n=13)

# Educational provision - Ireland

Type of provision	2007/8 or *2008/9
Mainstream	2, 571 (general)* + 198 classes (autism specific)
Special	170 (general)* + 101 classes (autism specific)
Home Tuition 2007/8	500
July Provision: school	78 schools (cf. 21 in 2001)
July Provision: home	1650 children (cf. 116 in 2002)
Total estimated no. in educational provision	5, 275 aged 5-18yrs (cf. 6,026 estimate aged 0-18yrs)

# Growth in autism-specific provision



- x5 increase in mainstream primary schools
- x2 increase in special schools
- first appearance in mainstream post primary schools

# Provision in flux?

- Court cases + parental pressure for early intervention programmes using Applied Behavioural Analysis (ABA) methods
- EPSEN Act 2004 → *appropriate and inclusive education*
- Budget decision Oct 2008 → EPSEN deferred
- ABA pilot scheme not to be expanded
- Funding for expansion of North-South centre of excellence for autism services on hold
- Very timely to consider needs of children and young people on the autism spectrum in this context

# Educational interventions for ASD

- Wide diversity across the spectrum in terms of:
  - Severity of autistic characteristics
  - Intellectual ability
  - Personality
  - Sensory processing
  - Family characteristics
  
- Importance of conducting a thorough assessment across all areas, to determine the nature and level of a child's needs

# General limitations to research

- ❑ More than one intervention
- ❑ More than one component
- ❑ Lack of assessment / diagnostic information
- ❑ Small sample sizes
- ❑ Short-term outcomes
- ❑ Weak methodological designs
- ❑ Lack of independent evaluation
- ❑ So, personal and professional knowledge of CYP remains very important

# Guiding principle

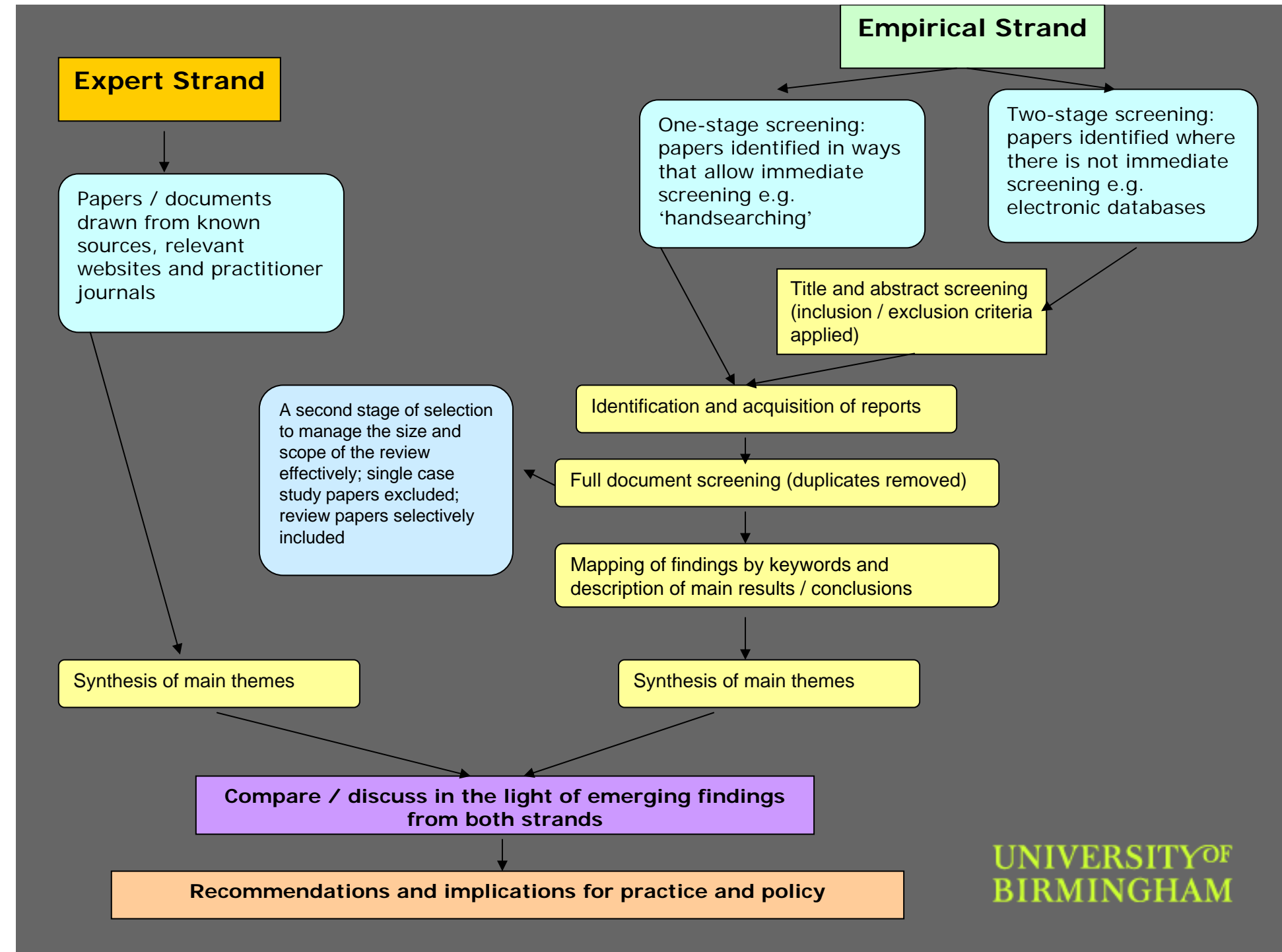
- Task Force Report (2001) noted that:

*‘Information on a variety of empirically validated methodologies should be available and the relative value of different options should be explored from the professional and parental perspectives before making decisions on educational placement’ (section 4.12, recommendation 10).*

- Empirical evidence, in conjunction with expert views, is essential in making judgments about educational provision

# Method

1. *Empirical Strand:* systematic searching of electronic databases focusing on empirical studies
2. *Expert Strand:* selective collation of articles, reports, reviews and guidance based on expert opinion / professional experience



# Empirical strand

- 'As systematic as possible':
  - Agreed definitions of terms
  - Clear inclusion and exclusion criteria
  - Quality assurance
  - Grading evidence to identify 'high' quality
- Cf. guidance from the Evidence for Policy and Practice Information and Coordinating Centre (EPPI-Centre); Institute of Education, University of London
- Initial list of 499 reduced to 100 for full review

# Empirical - main themes

- Multi-component interventions
- Comparison of different types of interventions
- Home-based interventions and impact on parents
- Social interaction, understanding and skills
- Specific learning tools and approaches
- Voices of children, young people and adults
- School staff training
- Parent training/ involvement

# Expert strand

- Dated 2002-2008 only
- Policy guidelines and reports from Ireland (n=6) and UK (n=7) only
- Greater similarities between these systems
- Plus targeted searching for post-compulsory education literature (n=11)
- Reports based on personal or organisational opinions excluded
- Total = 24

# Expert - main themes (1)

- Children and young people:
  - Early assessment and intervention
  - Staff training
  - Working with families
  - Multi-agency approach
  - Types of intervention
  - The Autistic Voice
  - Transition to adulthood

# Expert – main themes (2)

- Post-compulsory education / adults:
  - Transition
  - Social skills curriculum
  - Multi-agency approach
  - Improving access to Further / Higher Education
  - Institutional considerations
  - The Autistic Voice
  - Diagnostic disclosure

# Mapping the evidence

- Different aspects of provision covered by different evidence strands
- Supports the rationale of drawing on evidence from beyond the peer-reviewed literature
- For example, multi-agency working and transitions → only commented on in the expert strand

	Empirical	Expert: Children and young people	Expert: post-compulsory education and adults
Early assessment and intervention	✓	✓	✓
Types of intervention	✓	✓	
Working with families	✓	✓	
Multi-agency approach		✓	✓
Staff training	✓	✓	
Social skills curriculum			✓
Social interaction, understanding and skills	✓		
Specific learning tools and approaches	✓		
The Autistic Voice	✓	✓	✓
Transitions		✓	✓
Improving access to Further / Higher Ed			✓
Institutional considerations			✓
Diagnostic disclosure			✓

# Mapping: empirical studies

<b>Age of participants</b>	49% of studies included preschool children
	33% primary aged children
	10% secondary aged
	8% post-compulsory education and adults
<b>Numbers of participants</b>	48% included 11 or fewer participants
<b>Geographical spread</b>	59% North America
	26% UK
	7% Rest of World
	5% Europe
	3% Ireland

# Quality of evidence

- Only 12 out of 100 empirical articles rated as 'high' weight of evidence, focusing on:
  - Preschool children
  - Comparisons of early interventions
  - Use of PECS
  - Involvement of parents in supporting development, esp. early communicative behaviours
- **Remainder:** small sample sizes; highly variable rates of responding; weak research designs
- **Underscores difficulties in carrying out robust, meaningful research in the real world**

# Main findings (selected)

- Growth in specialist provision in Ireland: *an appropriate and inclusive environment?*
- Lack of evidence in Ireland, UK and beyond  
→ no empirical evidence focused on this
- Highlights practice outpacing the evidence base rather than questioning appropriateness
- Expert evidence strongly supports maintenance of range of provision to cater for diversity of need
- This should be available in mainstream and specialist settings

# Focus on early intervention

- 82% of empirical studies focused on younger children (preschool and primary)
- Highlights importance of early intervention
- Focusing on early communicative behaviours shows particular promise (eg. joint attention)
- BUT, older children and young people, and adults relatively neglected in the literature
- More research urgently needed to address this

# Comparing effectiveness of interventions

- Early years; intensive behavioural (IB) programmes vs. others; robust methodologies (5 out of 10 articles = High WoE)
- IB techniques successful in teaching specific skills, for some children, in some contexts
- Robust comparisons produce mixed findings across studies
- *One particular type of intervention or approach is unlikely to produce the best outcomes for all children included*

# Importance of parents

- Parents can make important contributions to educational interventions for their children
- Need to be equipped with good psycho-educational information in order to do so
- Family contexts and wishes need to be taken into account when considering any intervention
- Parental stress levels are an important influence on successful outcomes

# 'Voices' of CYP and adults with ASD

- Strong emerging findings from empirical and expert strands
- Importance of taking views and experiences into account
- Vital to informing good practice provision
- Qualitative evidence re views and experiences much needed

# Some important gaps

- Relative dearth of published empirical research relating specifically to Irish context (eg. July provision, Home Tuition, IEPs)
- Multi-agency working recommended through expert strand but little published evidence about how, who, when and where
- Longer term outcomes + independent evaluation
- Lack of research on 'inclusive contexts' → qualitative research, incl. user views could be highly informative

# Overall

- Plenty of research but little that genuinely informs 'good practice' across all stages and types of provision
- Plenty of 'practice' out in schools with scant / no supporting evidence
- Significant disconnect between research and practice
- Lack of collaborative, innovative and authentic research combining rigour and contextual / qualitative information

# Conclusions

- Children and adults with ASD are not a homogeneous group
- Decisions regarding education should be based on individual needs and preferences + views of parents, practitioners and providers
- One type of approach or intervention is unlikely to be effective for all
- A range of provision should be maintained in order to meet diversity of need
- Ongoing research is required to establish the effectiveness of interventions and types of provision

# Recommendations

- Seven key recommendations
- These are rooted in **findings** from both the empirical and expert strands
- They are drawn from the **implications** related to the themes
- They take into account **gaps in available evidence**

# Recommendation 1: Evidence Based Practice

- More empirical research is needed on what constitutes an inclusive education for individuals with ASD
- There is a need for robust designs that allow for differentiation of variables and identification of salient factors

# Recommendation 1: Evidence Based Practice

This research needs to:

- Examine effectiveness of provisions
- Evaluate the impacts of a range of interventions
- Study a range of age groups and subgroups
- Take into account family characteristics and individual contexts
- Take onboard the perspectives of users

## Recommendation 2: ASD Provision and Pedagogy

- There is no evidence to suggest one intervention will meet the needs of all learners
- A range of options should be available (settings and interventions)
- These need to fit the profile of the child or young person with autism

## Recommendation 2: ASD Provision and Pedagogy

- Early intervention should remain a priority
- Interventions that focus on early communicative behaviours are important
- The needs of older children are under-researched
- Learning through interaction with peers is crucial
- For adults, there is a need to focus on emotional and social wellbeing

# Recommendation 3: Training

- Practitioners and parents need specialist knowledge
- It is a priority to ascertain training needs
- Studies should examine influence of training on practice and evaluate outcomes of individuals
- There is a need to develop training pathways

# Recommendation 4: Working with Families

- Parent training is a priority
- There is a need to put in place mechanisms to make training widely accessible
- Parents need accessible information on educational settings and interventions
- It is important to reach families that do not access opportunities and services that are available

## Recommendation 5: Multi-agency approach

- There is a need to formalise multi agency responsibilities and protocols
- Coordination of services from education, social care, health, voluntary and independent sectors is important
- Research studies on multi-agency collaboration are needed
- There is a need to emphasise joint working

# Recommendation 6: The Autistic Voice

- Children and adults can provide important insights about which supports are effective
- Guidelines need to be developed to ensure views should be sought
- There is a need for more qualitative methodologies in this area
- Advocacy and self advocacy groups can offer important insights

# Recommendation 7: Transition Planning

- Transition is generally an extreme source of distress
- Detailed planning for transition is needed
- Practitioners and parents need guidelines to inform good transition practice
- There is a need to formalise links between schools and further and higher education providers

Thanks for listening😊

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