



Autism Spectrum Disorder and Future Challenges:

How can we contribute to the research agenda?

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***"The changing pattern of childhood disability" professional practice and
research***

**Lorimer Dods Lecture Theatre, The Children's Hospital at Westmead,
Sydney, Australia
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A Case Study of Sunfield

We recognise that we are working with young people who have extremely complex lives. ***We simply do not have all the answers.***

Sunfield is a learning community – ***we learn and develop together.***

Our Aims:

- ❖ To develop our understanding of the nature and impact of severe and complex learning difficulties, including autistic spectrum disorders.
- ❖ To find new and improved ways of supporting our young people and their families.

Sunfield provides a range of services to children with Autistic Spectrum Disorders and their families (e.g. Education, Outreach, Assessment, Family Services etc.)

The professions involved in those services are:

- **Education** -
 - Teachers
 - Teaching Assistants
 - Outreach Support Workers
 - Creative Arts Team

- **Social Care** -
 - Managers
 - Team Leaders
 - Care Support Workers

- **Therapy** -
 - Speech/Language
 - Occupational
 - Music

- **Psychology** -
 - Clinical
 - Educational
 - Developmental
 - Counselling

The professions involved in those services (continued...)

- **Health**
 - Nursing
 - G.P.
 - Psychiatry

- **Family Workers**

- **Training**
 - Staff Development
 - Research
 - ICT Team

- **Allied Professions**
 - Catering
 - Building
 - Estates

A total of 420 Staff

“Despite the clear biological base to ASD’s there are as yet no reliable and valid biological markers”

*(Jordan, R. (2005); Bauman & Kemper (1994);
Gillberg & Coleman (2001))*

Prevalence of autism

60 per 10,000 (1 in 166) children under 8 years

***Medical Research Council,
2001***

91 per 10,000 in the total population (1 in every 110 people)

***National Autistic Society,
2002***

1 in 800 school children (previously 1 in 1,000)

***Department of Health,
2002***

SUNFIELD – as a Research Organisation

‘It is easy for practitioners to become over-awed by the concept of research and perceive it as a lofty academic concern removed from their own activity’

Carpenter, B. (2006 – in press)

“The fact that most evaluation is by the practitioner increases the chance of bias and contamination. However, statistically based results are of limited value to the practitioner trying to decide the best approach for a particular child in a particular context. Most research designs focus on programmes developed to meet group needs whereas it may be more important to know about the individual characteristics that led to success and/or failure” (pp116-117)

*Jordan, R. (2005) 'Autistic Spectrum Disorders
In A. Lewis & B. Norwich (Eds) Special Teaching for Special
Children?*

*Pedagogies for Inclusion
Berskhire: Open University Press*

“Action research models or single subject designs may offer more ecologically valid ways of evaluating particular programmes with particular children in particular settings”

Odom, S.L. et al (2003)

*‘Evidence-based practices for young children with autism; contributions for single subject design research’
Focus on Autism and Developmental Disabilities,
18, 166-175*

“Work with me to build bridges
between us”

*Sinclair, J. (1992) 'Bridging the Gaps: an inside-out
view of autism'. In E. Schopler & G. Mesibov (Eds),
High Functioning Individuals with Autism.
New York: Plenum Press*

“(We must find) approaches that seek partnership in bridge building and which acknowledge both the starting point of our partners with autism and the efforts they make in trying to connect”
(p120)

**Powell, S. (2000) ‘Helping Children with Autism to Learn’
London: David Fulton**

“We now know so much about childhood disability that we must move to second generation research.

This must be practitioner led and evidenced based”

Michael Guralnick (2004)

**What is the purpose of our
research?**

**“Understand the new
challenges and change in
order to go forward”**

*Clare Short
December 2004*

To...

- Enquire
- Investigate
- Gather data
- Analyse
- Report
- Search
- Explore
- Study
- Probe
- Evaluate
- Observe
- Collect evidence
- Disseminate
- Read

From the 'Core principles for research-informed professional practice'

- Develop new ideas and concepts from a foundation of existing good practice and theory.
- Create, interpret, share and rigorously evaluate practical evidence about teaching and learning in and for different contexts.

(GTC Research Digest, 2004)

Research Outcomes

- for children
- for their families
- for professionals

Important questions to ask:

- What influence will my research have?
- What contribution will it make on the lives of people with special needs/disabilities?

*From: Porter, J., Lacey, P. (2005)
'Researching Learning Difficulties'
London: Sage*

Who should research?

All staff working directly with children and their families have a contribution to make at some point along the continuum of research

To disseminate research and practice outcomes

To investigate new challenges presented by the student population

To create new pathways to learning and care

To enhance each individual's contribution to research

To gather and utilise current knowledge in the field to inform reflective practice

To develop high standards of best practice across Sunfield professional groups

AIM
Research at Sunfield will result in ongoing development of new and innovative best practice to enhance the quality of life for its children/young people

To generate evidence to support practice styles

To empower and value all staff and families as active participants in a research culture

To undertake research in a transdisciplinary context

To evolve research methodologies that reflect the students' perspectives

To ensure practice is ethical

To stimulate a reflective community

Features of a Robust Research Process

- Integrity
- Rigorous
- Well planned
- Careful execution
- Meticulous reporting
- Transparent
- Ethical

From: Porter, J., Lacey, P. (2005)

The tangibility factor...

Data already 'owned' by staff, families and students

- Daily logs
- Review reports
- Personalised learning targets
- Curriculum records
- Briefing sheets
- Functional analysis reports
- End of term reports
- Behaviour Development Plans
- Family Survey
- Operational Plan (School Improvement Plan)
- Inspections
- Student Council surveys

‘Researching *with*, rather than *on*, people with disabilities is an important distinction and must guide the motivations and actions of all who engage in the process, (p. 47)

Rose, R. (2002) ‘Teaching as a ‘research-based profession’: encouraging practitioner research in special education’, *British Journal of Special Education*, 29 (1), 44-48

Experience in promoting their data

- Assignments
- Presentations
- Child planning meetings
- Hosting visits
- Student placements
- Sharing information (inter-agency teams)
- Collaboration with other organisations

Support available for reflective practice and knowledge development

- Training opportunities
- Articles for publication
- Papers for conferences
- Delivery of external training
- Innovations forum

Supporting research – how?

- Research Officer
- Research policy
- Research and Ethics Committee
- Research scholarships
- Briefing sheets
- Staff library
- Journal subscriptions

Assignment-based Research

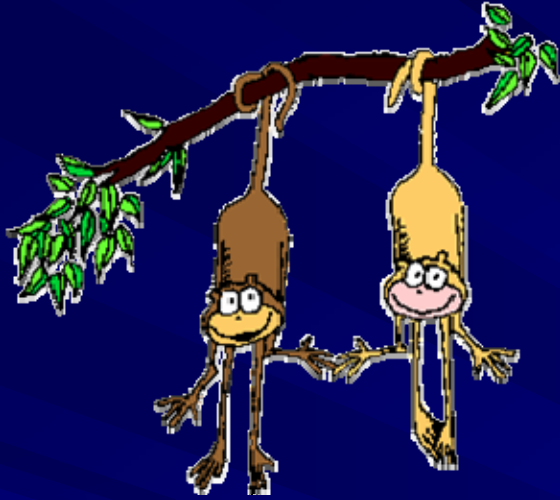
- Transition
- Informed choice
- ICT
- ASD-specific practices
- Sensory approaches

Role-based Research

- Evaluating staff training
- Social stories
- Counselling
- Perceptions of disability
- Inclusion
- Siblings
- Health resources

Organisation-based Research

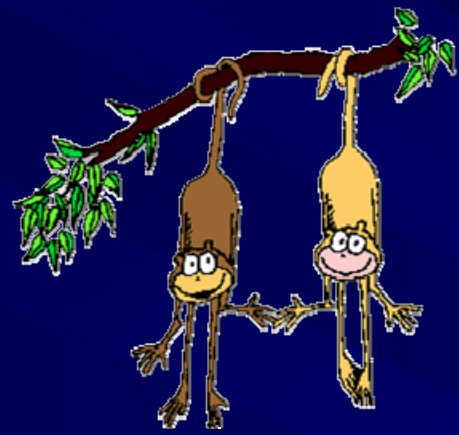
- Peer Mentoring
- Diet and nutrition intervention
- Families' experience of induction
- Drama-based inclusion project
- Mental health
- An evaluation of an autism-specific living environment



The Monkey King Project

Researching Pupils' Perspectives on Inclusion and Disability

Whitehurst and Howells (2006)
Published in
'Support for Learning' 21 (1) 40-44

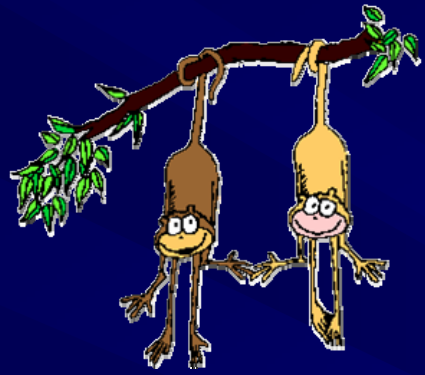


Who was involved???

- 23 Hagley Middle School Children (age 12)
- 6 Sunfield Students
- Open Theatre (Shysters) – Coventry
- Sunfield Staff
- Beyond Monkey King Team

Research Phases

- **Phase One** : How perceptions held by mainstream pupils changed as a result of working alongside peers with autism and severe and complex learning difficulties
- **Phase Two**: What have the children told us about how inclusion can work?
- **Phase Three** : What impact the project had upon the young people with autism and severe and complex learning difficulties

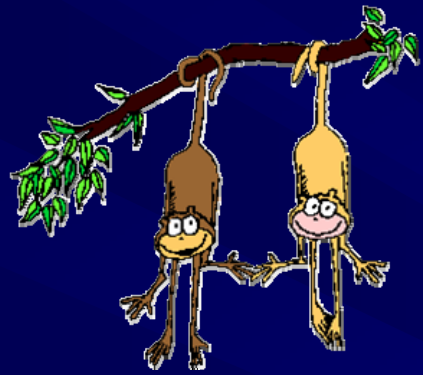


Design for Phase One

- Face to Face interviews
- Collaboration
- One researcher paired with one student
- Questions based on a distinction between perception and knowledge

Phase One

Interview Questions

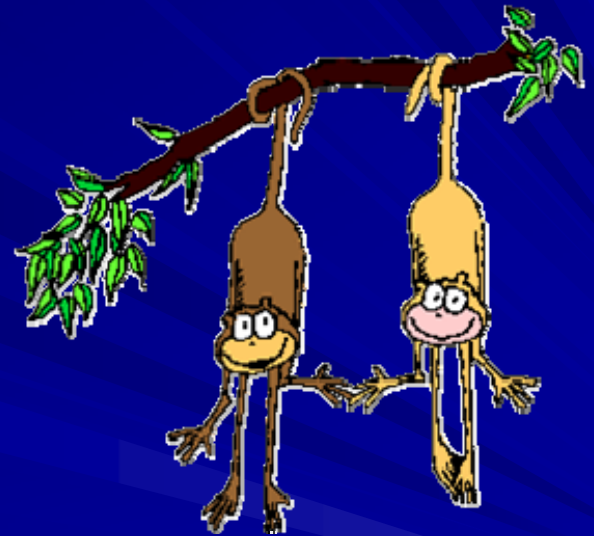


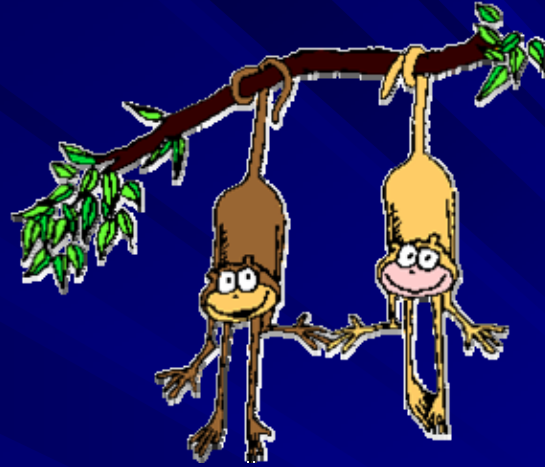
- What was their knowledge base regarding learning disability and autism?
- What did they think of people with learning disabilities & autism ?
- Do they know any more about learning disabilities and autism now?
- What do they now think of people with learning disabilities & autism?
- How has this project helped them develop as an individual?

“What was their knowledge base regarding learning disability and autism?”

Dominant Theme : Limited Factual Knowledge

- *“I didn’t know whether they would have mild or severe dyslexia”*
- *“My cousin had brain damage so I had some explanation of autism”*
- *“I knew because one of my family members had a brain tumour and was unable to do things”*





Qu 2: What did they think of people with learning disabilities & autism?

Theme 1 : Don't see them as 'people'

- *"I knew they existed"*

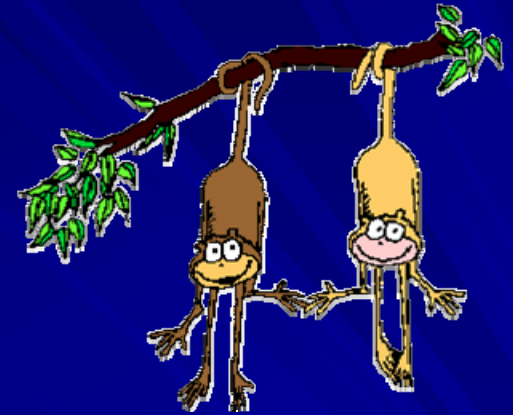
- *"I'd seen people like that at Merry Hill Shopping Centre"*

- *"Sometimes I didn't see them as people"*



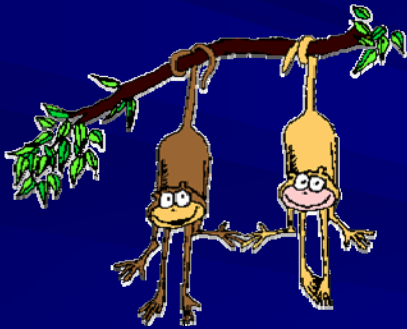
Theme 2 - Perceptions of Difference

- *“I thought they were strange and different – they were strangers and I wasn’t used to them but they were different to normal strangers”*
- *“They are completely different to us”*



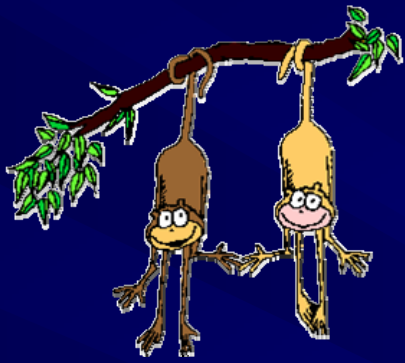
Theme 3 - Lack of understanding

■ *“They weren’t like us – I thought they would be more delicate”*



■ *“I thought they’d be walking around not knowing anything”*

■ *“I thought they were different and I was scared to touch them...I thought I may get what they get if I touch them”*

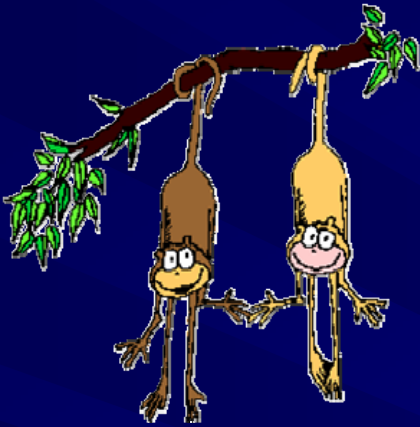


Theme 4 - Their own abilities

- *“I was frightened because I didn’t know how they would react”*
 - *“I didn’t know how to approach them – I was apprehensive – didn’t know what to expect from them”*

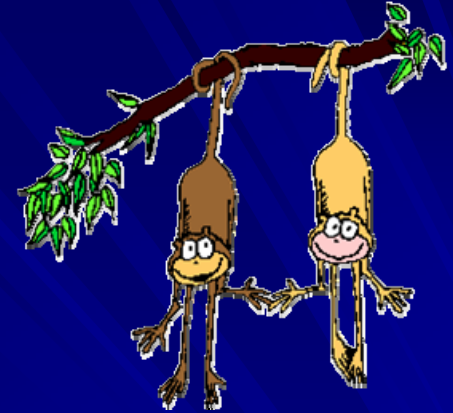
- *“The first time I saw them I was shocked”*
 - *“ I mean.....how are you meant to act around them? What are you meant to do? I was worried”*

Had their Knowledge base changed?



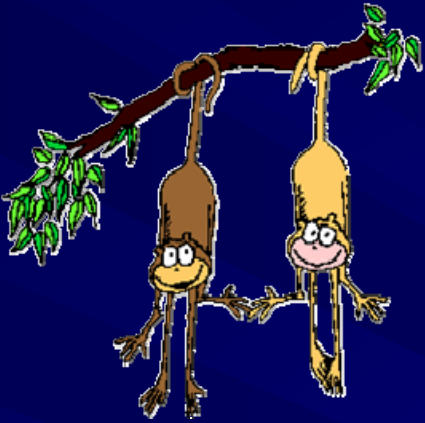
- Not really but.....
- Shift in understanding had occurred
- *Practical knowledge* as opposed to *factual knowledge* appeared to be the key.

Emerging Theme: Practical vs Factual



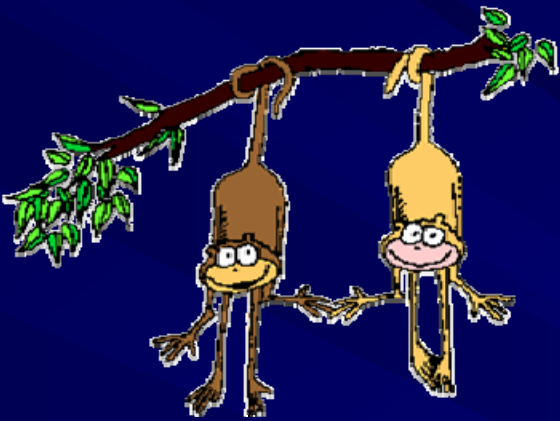
- *“I think knowing more about them helps – like knowing what they can and can’t do”*
- *“I know what they’re like so I can cope with it”*
- *“I don’t know about their condition but more about the person”*

Emerging Theme: Shift In Understanding

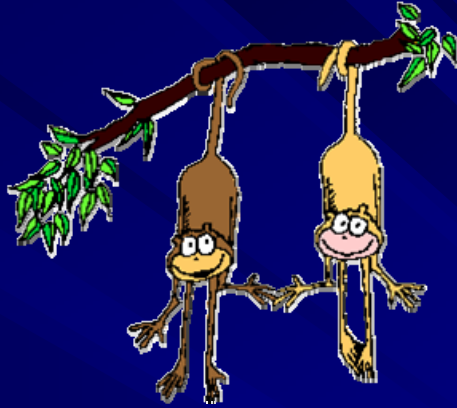


- *“They have problems but they’re all different. You have to know each one to know how to treat them and how to talk to them”*
- *“They’re normal – you see past the disability and don’t just judge them by that”*

Summary

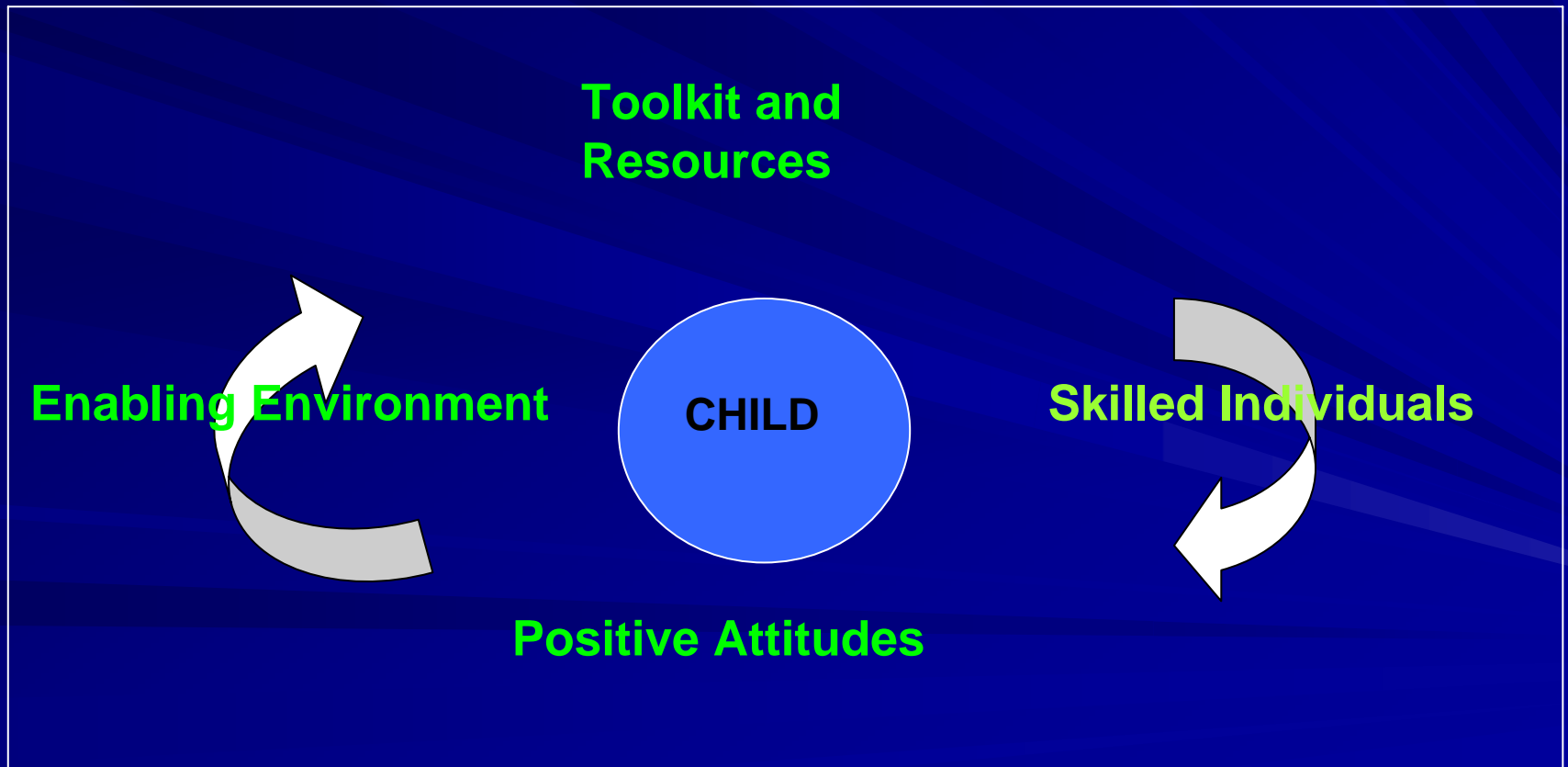


- Perceptions of children with disabilities were more positive but this was not related to increased knowledge of disabilities per se
- Practical skills acquired were more important than factual knowledge
- Pupils own abilities to manage the situation were more important than their understanding of disability
- Feelings of their own lack of preparedness and the unfamiliarity of the situation did not enable them to predict the future context



***“When something is different
people fear it”***

Cyclical Process of Positive Social Construction



**From practice to research....
from research to practice**

Further Information

Whitehurst, T. (in press) 'Liberating Silent voices – Perspectives of Children with profound and complex learning needs on inclusion'.

British Journal of Learning Disabilities

Whitehurst, T. & Howells, A. (2006) 'When something is different people fear it – children's perceptions of an arts based inclusion project'. *Support for Learning* 21 (1) 40-45

www.sunfield-school.org.uk

Externally funded

- Developing Social Engagement through Movement
- Curriculum resources to support children's emotional wellbeing
- 'Transition Solutions': pathways to adulthood

Future Projects

- Voice for Choice
- Sleep problems in children with autism

International Fellowships

A comparative evaluation of
pedagogical styles with children with
Autistic Spectrum Disorder

*Onur Kurt, Teacher/PhD Student
University of Anadolu, Turkey*

Recent publications and presentations

- Effectiveness of TEACCH
- Transition to adulthood
- Experiences of siblings
- Family-centred training model
- ICT for children with profound ASD
- Colour Impact Project (Ph.D.)
- Perspectives on Inclusion and Disability

Key messages

- Research - focused

through asking ethical questions that improve our knowledge and understanding of the children and the quality of our service to them

- Evidence - based

through robust recording of children's development progress and attainment, reflecting on our practice

- Family - oriented

through resources and support that enable families to grow in their love and commitment

- Child - centred

through individually tailored, high quality education, care, psychology and therapeutic services

'If educational research is to change practice for the better, it can...only do this by operating through the minds and the understanding of practitioners'

(Wilson, 2002)