Early intervention for Autism Spectrum Disorder

Comparing international policies with developments in NI

Professor Karola Dillenburger (QUB)
Autism Spectrum

Karen Siff Exkorn, author of *The Autism Sourcebook* and her son Jake
Autism Spectrum Disorder

Social communication deficits;
Restrictive interests and repetitive behaviours; Sensory issues.

Diagnosis

Behavioural observation;
Parent/caregiver reports of behavioural observations;
There are no medical tests.

NI: 2% of school-aged children affected (DHSSPS, 2014).
“Autism: A lifelong disability”? 

Autism does not only affect children --- Adults with autism

Concept of “Lifelong Disability” limits expectations of trajectory; puts a ‘lid on expectations’.

NICE: replaces ‘lifelong’, with ‘a chronic disorder with lifelong disability in some individuals’.
Early Diagnosis

**Advantage**
- Access early behaviour intervention
- Access to carers/disability etc. benefit
- Impact on future

**Disadvantage**
- Lifelong label?
- Impact on future
Cost – Benefit analysis

Lifetime cost per person £0.9 – 1.4 million

Annual cost in the UK is £32.1 billion

Intervention: Savings up to £1 million across a lifetime
AUTISM INTERVENTIONS
THIS WAY
1999

Over 30 [45] years of research demonstrate the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. (Surgeon General, USA)
What is Behaviour Analysis

**Conceptual basis:** Radical Behaviourism
*from latin: radix - root/origin/essentials.
not: methodological behaviourism

**Basic science:** Experimental analysis of behaviour

**Applied science:** Applied Behaviour Analysis

Like other sciences, behaviour analysis is taught at Universities Masters/Doctoral level.

Professionally approved courses ([www.bacb.com](http://www.bacb.com))
‘Discovering environmental variables that reliably influence socially significant behaviour and develop interventions for behavior change that take practical advantage of discoveries from experimental analysis of behaviour’

(Baer et al, 1969; Cooper et al, 2007)
The U.S. Office of Personnel Management concluded that there is now sufficient evidence to categorize ABA as medical therapy rather than purely educational.
2012
Capitol Hill: American Academy of Pediatrics publicly **endorsed the use of ABA treatments** (AAP).
A growing evidence base suggests that behavioral interventions can be associated with positive outcomes for children with ASD. (Vanderbilt University):
GREEN - States (37 + District of Columbia; US Virgin Islands) with enacted autism insurance reform laws
Ontario Ministry of Education (2007) Policy/Program Memorandum No. 140 “established a policy framework to support incorporation of ABA methods into school boards’ practices.”
Canada

Ontario Superior Court of Justice (2005) ruling:

“The absence of ABA means that children with autism are excluded from the opportunity to access learning, with the consequential deprivation of skills, the likelihood of isolation from society and the loss of the ability to exercise the rights and freedoms to which Canadians are entitled”. (Justice Frances Kiteley)
Australia

2012

Department of Families, Housing, Community Services and Indigenous Affairs. (Australian Government)

ER = Eligible based on established research evidence: Applied behaviour analysis (ABA) or early intensive behavioural intervention (EIBI)

Northern Ireland

Autism Act (2011)


NICE guidelines for Diagnosis (2011); Adults (2012); Management of Children (2013).
None of these documents included any recommendation for ABA-based interventions.

“In the review of evidence, the Guideline Development Group found no evidence to support ABA, and therefore could not make a recommendation about ABA”. (NICE, 2013)
NI approach to autism: Eclectic

Def. eclectic: ‘deriving ideas, style, or taste from a broad and diverse range of sources’ (Oxford Dictionaries, 2010)

Eclectic intervention = ‘assortment of educational and therapeutic techniques that are as varied as the school districts from which they come’. (Chasson, Harris, & Neely, 2007, p. 402)
Eclectic approach to autism

TEACCH
Eclectic approach to autism

TEACCH

Sensory Integration
Eclectic approach to autism

TEACCH

PECS

Sensory Integration
Eclectic approach to autism

- TEACCH
- PECS
- Sensory Integration
- Floor time
Eclectic approach to autism

- TEACCH
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- Special Education
Eclectic approach to autism

TEACCH

PECS

Sensory Integration

Floor time

Son Rise

Special Education
Eclectic approach to autism

- TEACCH
- PECS
- Sensory Integration
- Son Rise
- Floor time
- Other manualised programmes
- Special Education
Eclectic approach to autism
NI approach to autism: Eclectic

One fits all approach.
Comprehensive training is impossible.
Who makes decisions about what to include/exclude?
No coherent theoretical knowledge base.
Conflicting interventions.
Synergy effects can not be controlled.
No evidence of effectiveness.
UK approach: Eclectic
Long-term outcome

Participants: n = 60: individuals with autism, average IQ as children,

Measure: cognitive & language ability at 6 years and 44 years of age,

Findings:

n=15: untestable, severe aggressive or self-injurious behaviours, severe language delay,

n=45: IQ stable and language improved.

“many attended [eclectic] specialist autism schools as children none had access to the intensive, early behavioural [ABA-based] programmes” (Howlin et al., 2014, p.56)
International approach: ABA
Long-term outcome

Optimal Outcome: estim. 25-47% not meeting diagnostic criteria, not misdiagnosed.

Cost = 26 cents (15p) per member per month (PMPM);

Highly statistically significant link between Optimal Outcome and ABA-based interventions; early, around 1-3 years of age (Fein et al., 2013; Orinstein et al., 2014)
ABA: Common Category Mistake

Family
- Mother
- Father
- Child
- Aunt/uncle

Home
- Bedroom
- Living room
- Kitchen
- Bathroom

ABA
- DTT/‘LOVAAS’
- PECS
- VB
- Other individually tailored
Applied behaviour analysis for ASD

ABA knowledge and ethics
- All known principles of behavior
- Individually tailored functional assessment and functional analysis
- Data-based decision making

Person/Child-Centred
Applied behaviour analysis for ASD

ASD knowledge: ABA autism guidelines

ABA knowledge and ethics
- All known principles of behavior
- Individually tailored functional assessment and functional analysis
- Data-based decision making

Person/Child-Centred
Applied behaviour analysis for ASD

- Natural Environment
- ASD knowledge: ABA autism guidelines
  - ABA knowledge and ethics
    - All known principles of behavior
    - Individually tailored functional assessment and functional analysis
    - Data-based decision making
Applied behaviour analysis for ASD

**ASD knowledge: ABA autism guidelines**

**ABA knowledge and ethics**
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**Natural Environment Training**
- Discrete Trial Training
Applied behaviour analysis for ASD

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Applied behaviour analysis for ASD

- Natural Environment Training
- Discrete Trial Training
- Stimulus Control Procedures (e.g., PECS)
- Shaping & Chaining
- Verbal Behavior Systems
- Pivotal Response Training
- Early Intensive Behavioral Interventions

**ASD knowledge: ABA autism guidelines**

**ABA knowledge and ethics**
- All known principles of behavior
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Applied behaviour analysis for ASD

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- Natural Environment Training
- Discrete Trial Training
- Stimulus Control Procedures (e.g., PECS)
- Shaping & Chaining
- Verbal Behavior Systems
- Pivotal Response Training
- Early Intensive Behavioral Interventions
- Incidental Teaching
Applied behaviour analysis for ASD
Applied behaviour analysis for ASD

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Person/Child-Centred
Evidence Base

Thousands of replicated single-system design studies
Randomised controlled trials (RCT)
Meta analysis
Sequential meta analysis
Systematic reviews
Neuroscience (plasticity of brain)
Social validity measures
Cost – Benefit analysis

(e-mail me for 100s of references; NAC, 2009)
ABA: Changing the person?

**Autism:** Diagnosed on basis of behaviour

**ABA:** ‘Discovering environmental variables that reliably influence socially significant behaviour and develop interventions for behavior change that take practical advantage of discoveries from experimental analysis of behaviour’

(Baer et al, 1969; Cooper et al, 2007)
Socially Significant Curriculum

Determined by individual/parent/caregiver:

• Life skills: Dressing, toileting, attending, Social skills: Playing, imitation;
• Academic skills: attending, reading, drawing, writing, maths;
• Skills necessary to lead a fulfilled life.

“Skills development increases choice.”
Social validity measures

Social importance and clinical acceptability of
Treatment goals
Procedures
Outcomes

Parents say:
Over 90% social validity
Reduced stress levels
Research Bias

Who should conduct Dental Research?

OH, SO YOU'RE A BEHAVIOR ANALYST?
WHY DON'T YOU TELL ME ALL ABOUT GAINING STIMULUS CONTROL.
Research Bias

Who should conduct Meteorological Research?
Research Bias

Who should conduct Behaviour Analysis Research?

Nothing about us Without us!
### NEW REQUIREMENTS

<table>
<thead>
<tr>
<th>Research Methods in Behavior Analysis</th>
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<tbody>
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<td>Measurement (including Data Analysis)</td>
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<td>Experimental Design</td>
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<td>Discretionary</td>
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<td><strong>TOTAL</strong></td>
<td><strong>270 hrs</strong></td>
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Masters level (BCBA)
Doctoral level (BCBA-D)
(QUB and UU offer MScABA)

1500 hours of behaviour analytic practice under close supervision of a BCBA (at least 5% direct supervision)

The BACB examination
Takes 4 hour; 160 question
Pass rate 50-70%

Suitable for
supervisor/manager
HSC/ELB etc staff

www.bacb.com
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<td><strong>180 hrs</strong></td>
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Bachelor level (BCaBA)

1000 hours of behaviour analytic practice under the supervision of a BCBA (at least 5% direct supervision)

The BACB examination pass rate 50%

BCaBA practices under the supervision of a BCBA

Suitable for front-line HSC/ELB etc staff / teachers

www.bacb.com
Training requirements

40 Hours curriculum
(see QUB open Learning online RBT course)

Assessment by BCBA/BCaBA

Supervision BCBA/BCaBA

Should be required training for teaching assistants.

www.bacb.com
References


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.