



## 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*



## 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

## 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







# USA

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)



USA (population of 317 Million)





# 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))



# Applied Behaviour Analysis (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)



# USA

2012

The U.S. Office of Personnel Management concluded that there is now sufficient evidence to categorize ABA as **medical** therapy rather than purely **educational**.



# USA

2012

Capitol Hill: American Academy of Pediatrics publicly **endorsed the use of ABA treatments** (AAP).



# USA

2014

U.S. Department of Health and Human Services:

A growing evidence base suggests that **behavioral interventions** can be associated with **positive outcomes** for children with ASD. (Vanderbilt University):



# Autism Insurance Reform

2014



**GREEN - States (37 + District of Columbia; US Virgin Islands) with enacted autism insurance reform laws**



# Canada

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)**

[www.health.gov.au/autism](http://www.health.gov.au/autism)



# Northern Ireland

Autism Act (2011)

Autism strategy (2013-2020) and  
Action Plan (2013-2016)

NICE guidelines for Diagnosis  
(2011); Adults (2012);  
Management of Children (2013).



# Northern Ireland

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)**

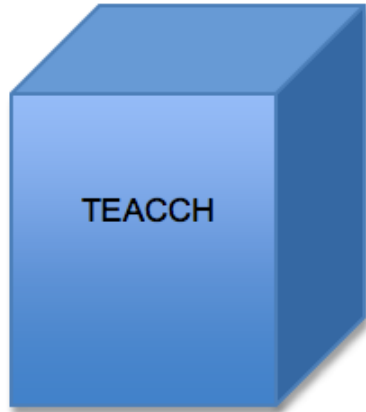


# NI approach to autism: Eclectic

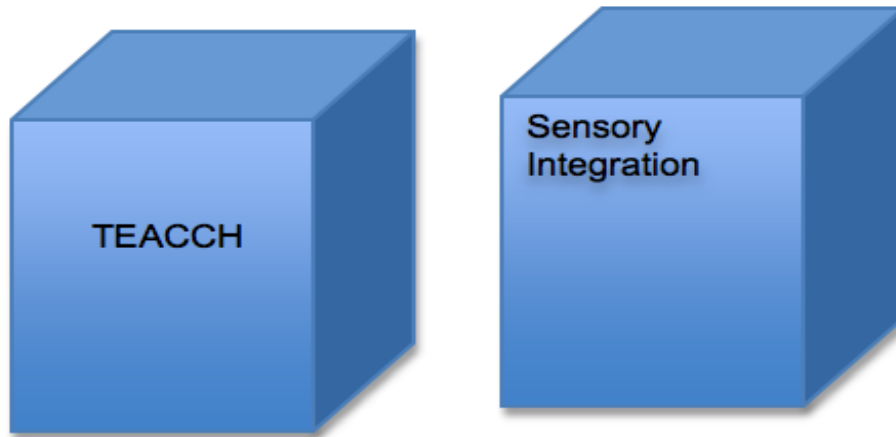
Def. eclectic: ‘deriving ideas, style, or taste from a broad and diverse range of sources’ (Oxford Dictionaries, 2010)

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

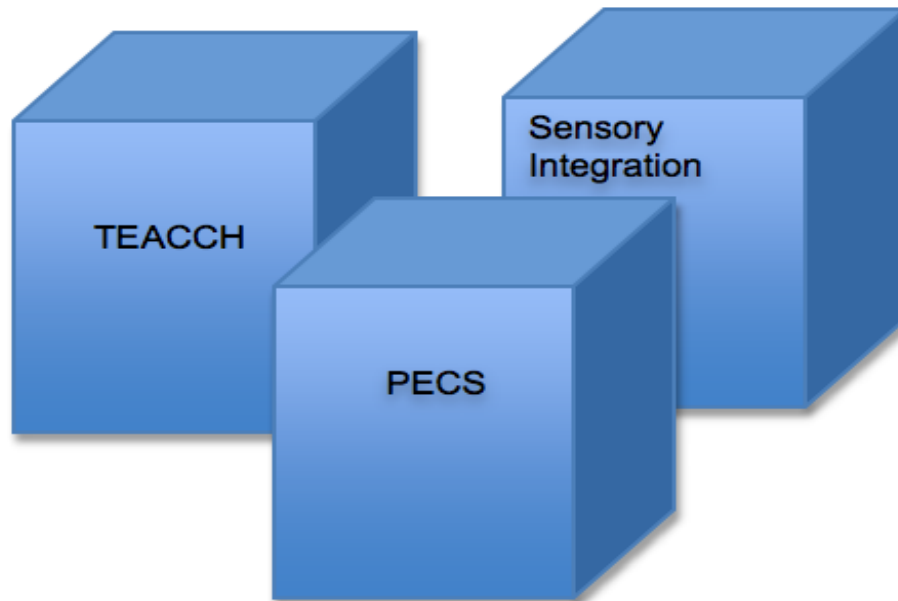


# Eclectic approach to autism

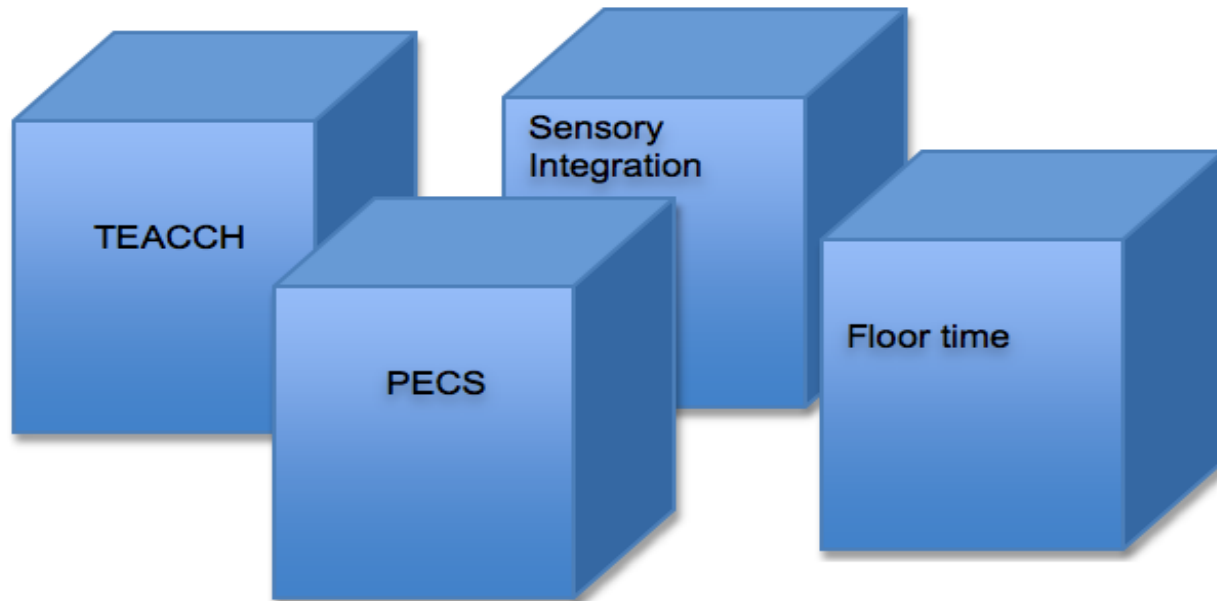




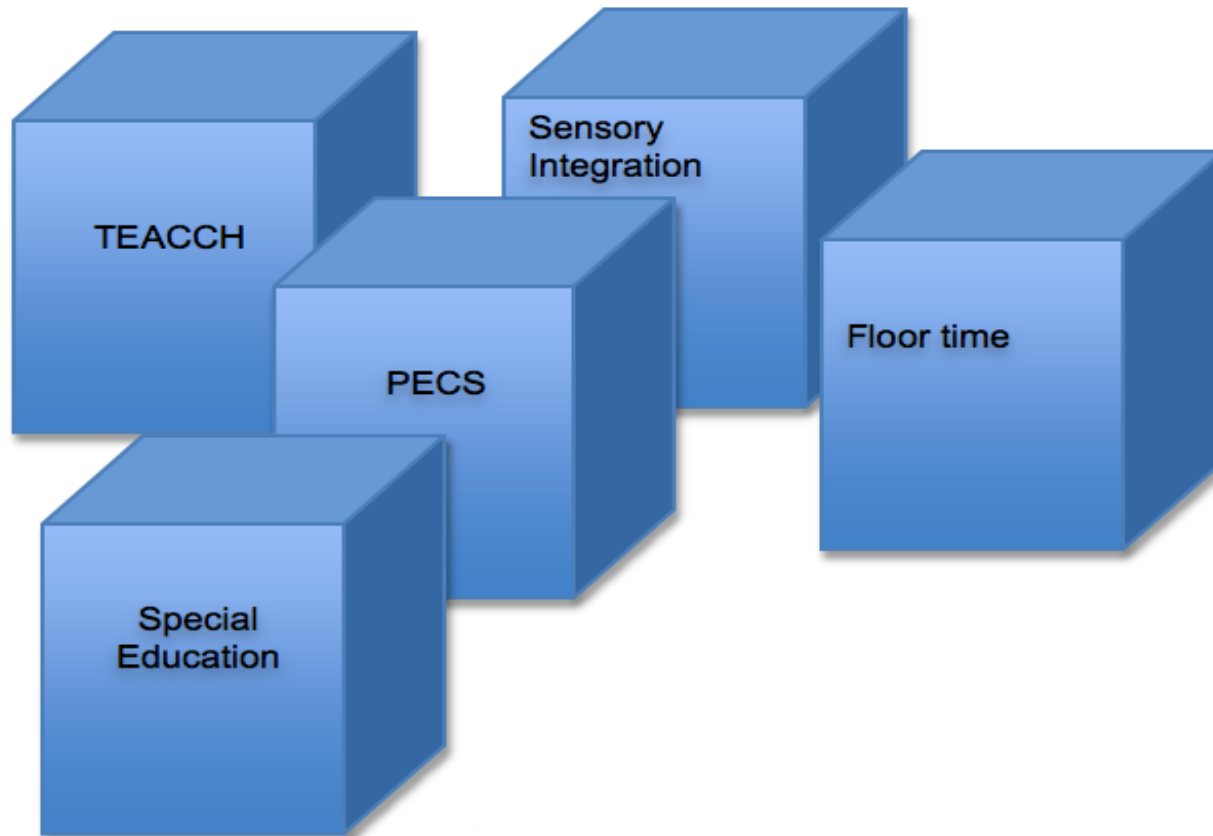
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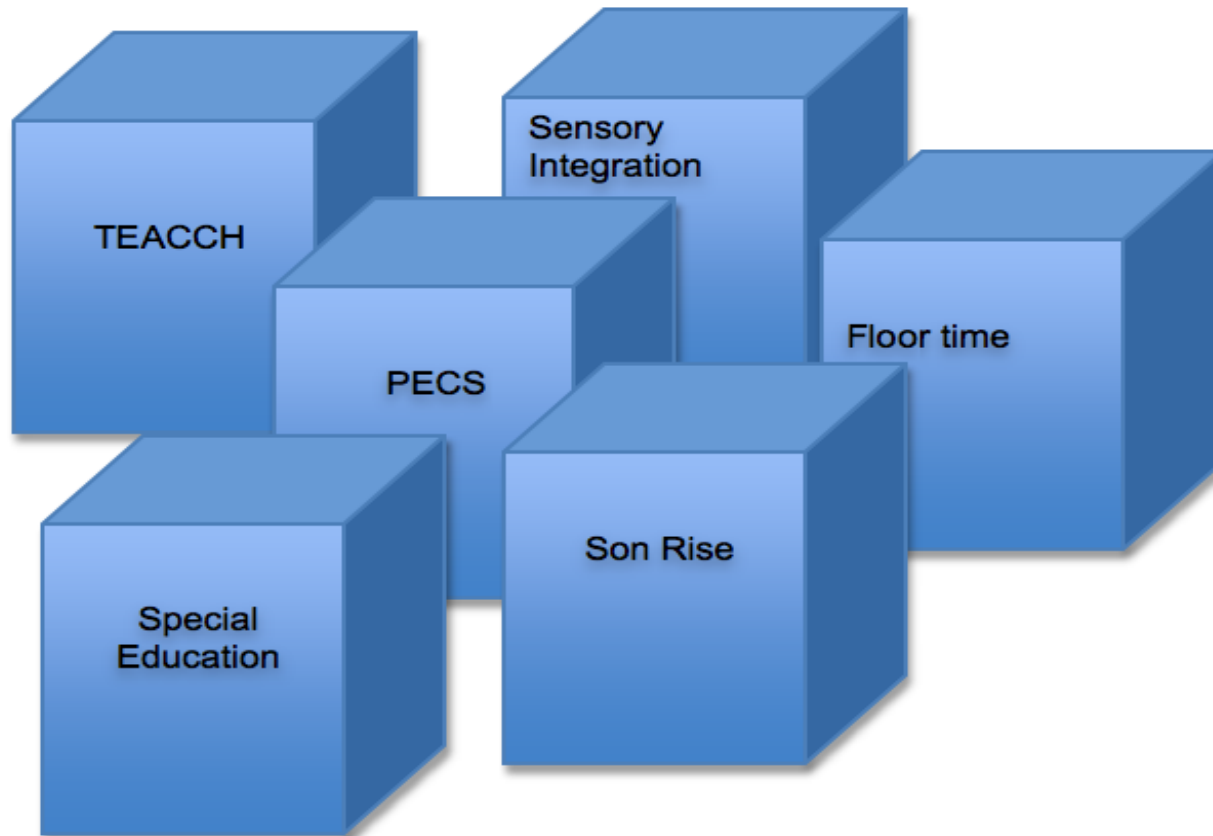
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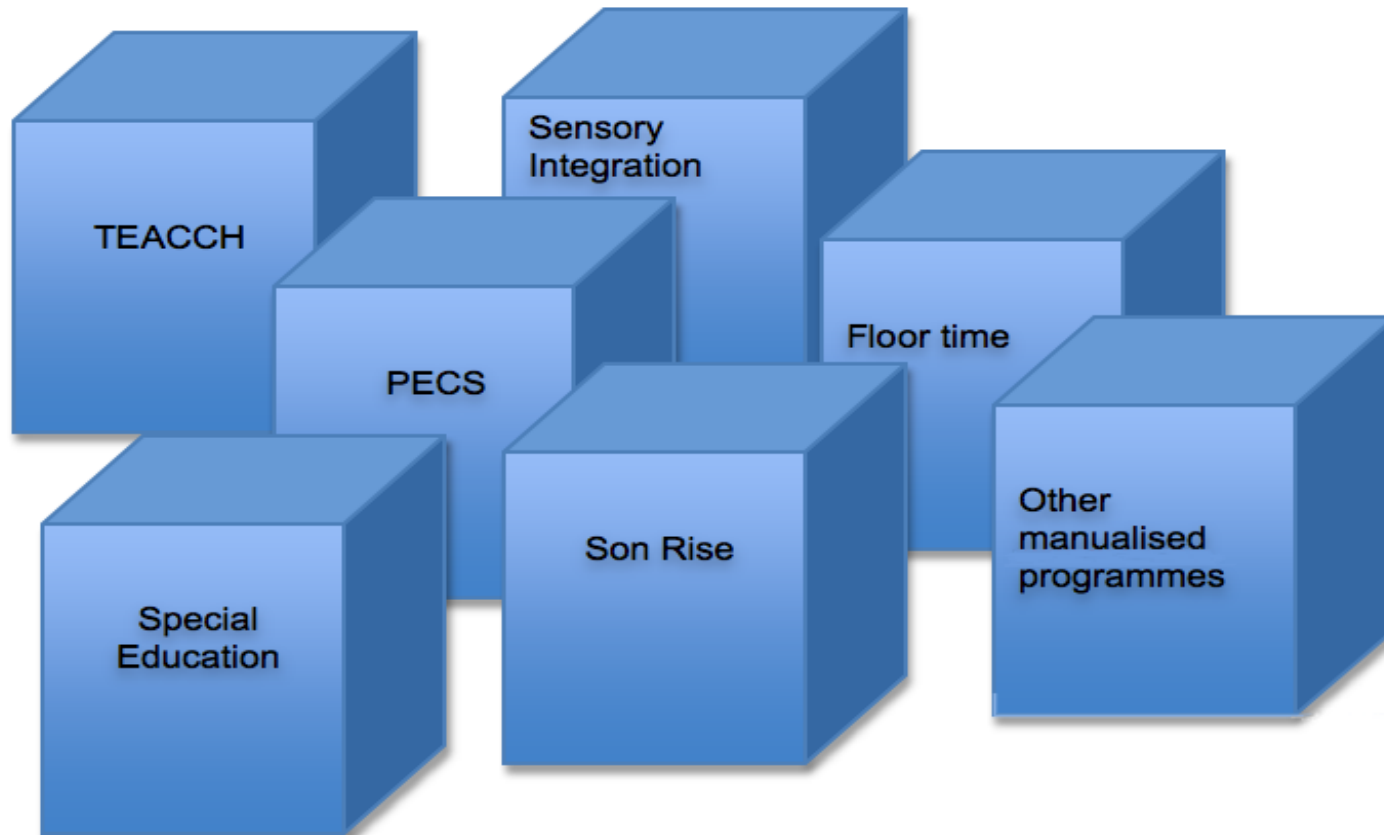
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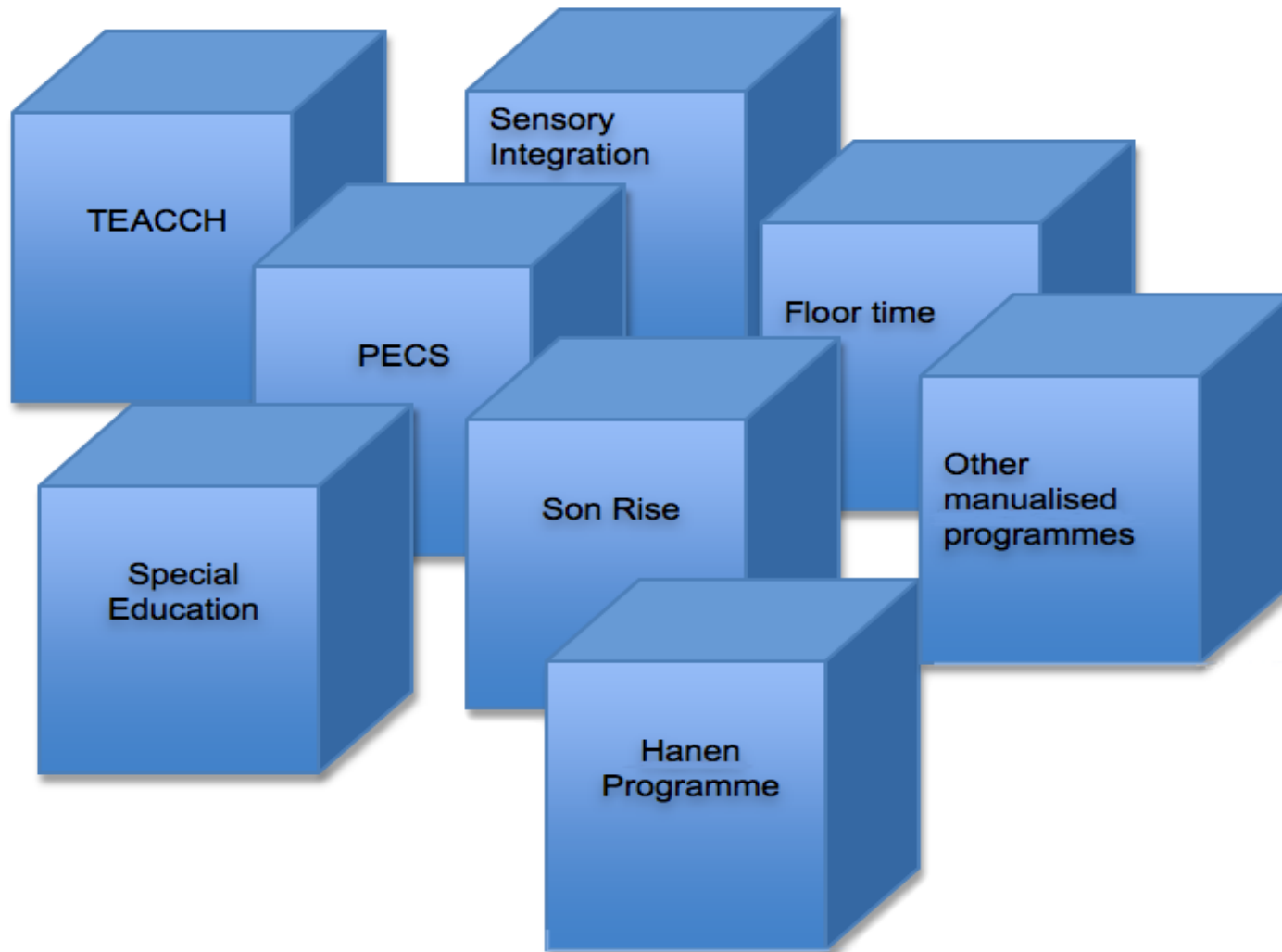
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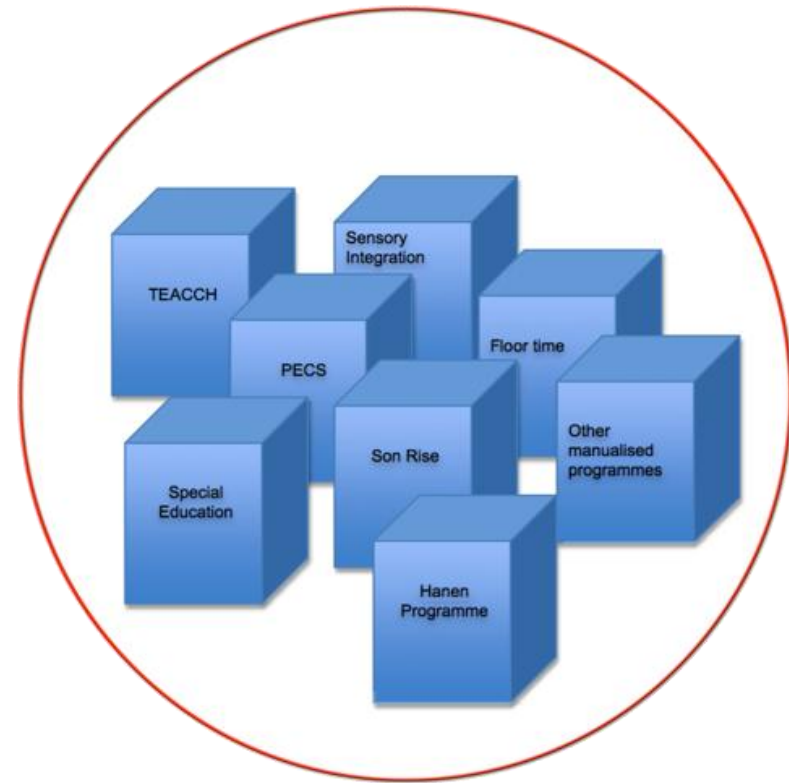


# Eclectic approach to autism



# 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

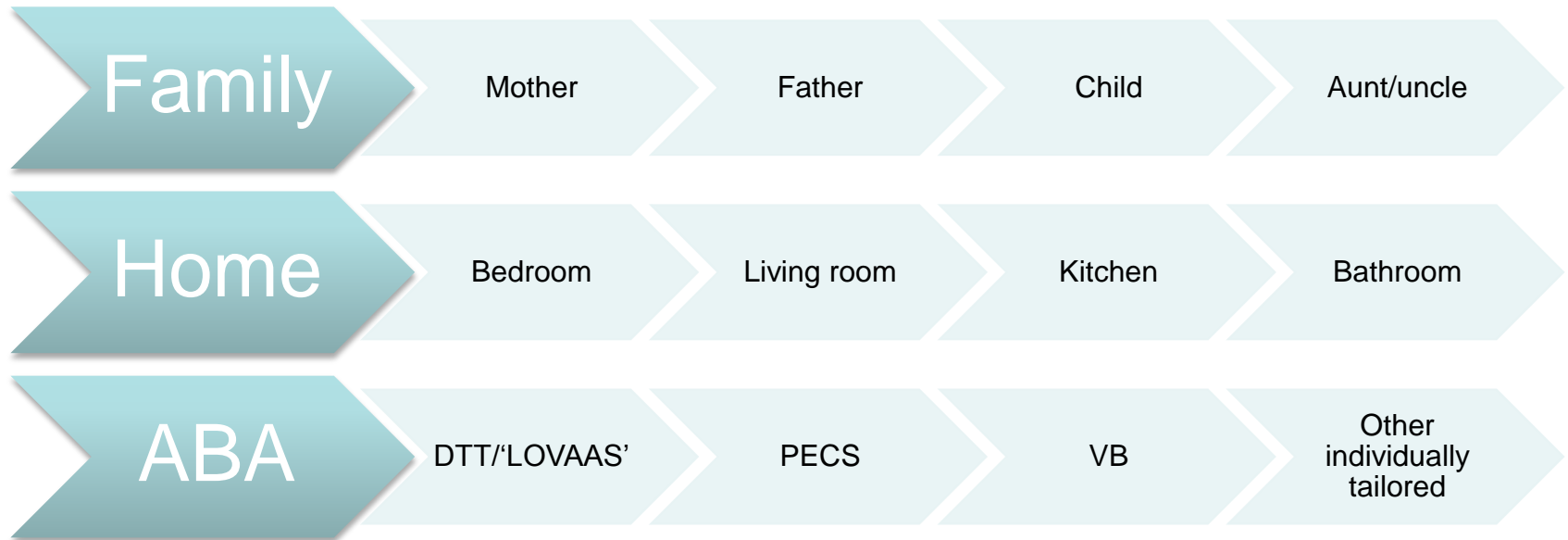
Optimal Outcome: estim. 25-47% not meeting diagnostic criteria, not misdiagnosed.

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

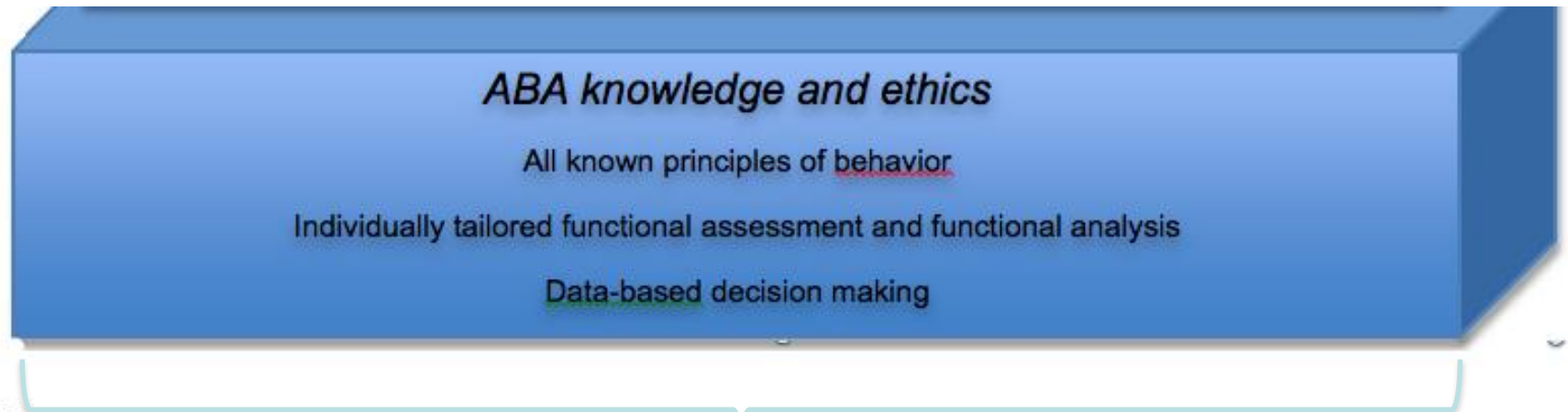
Highly statistically significant link between Optimal Outcome and ABA-based interventions; early, around 1-3 years of age (Fein et al., 2013; Orinstein et al., 2014)



# ABA: Common Category Mistake

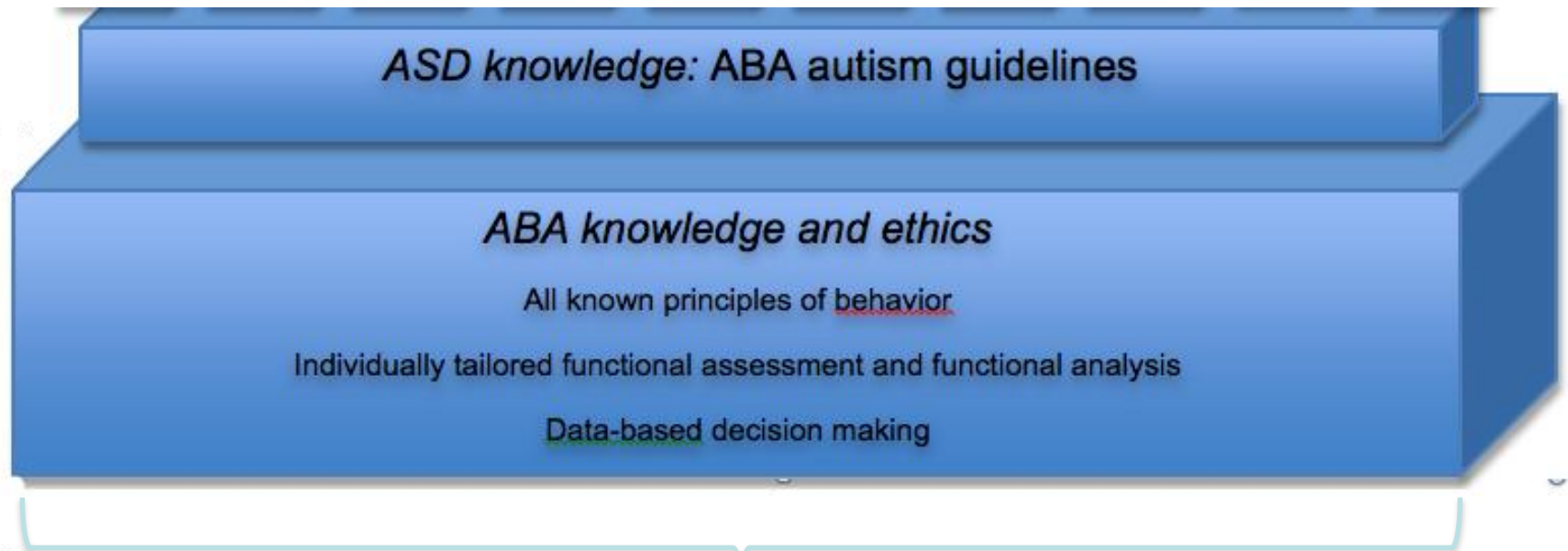


# Applied behaviour analysis for ASD



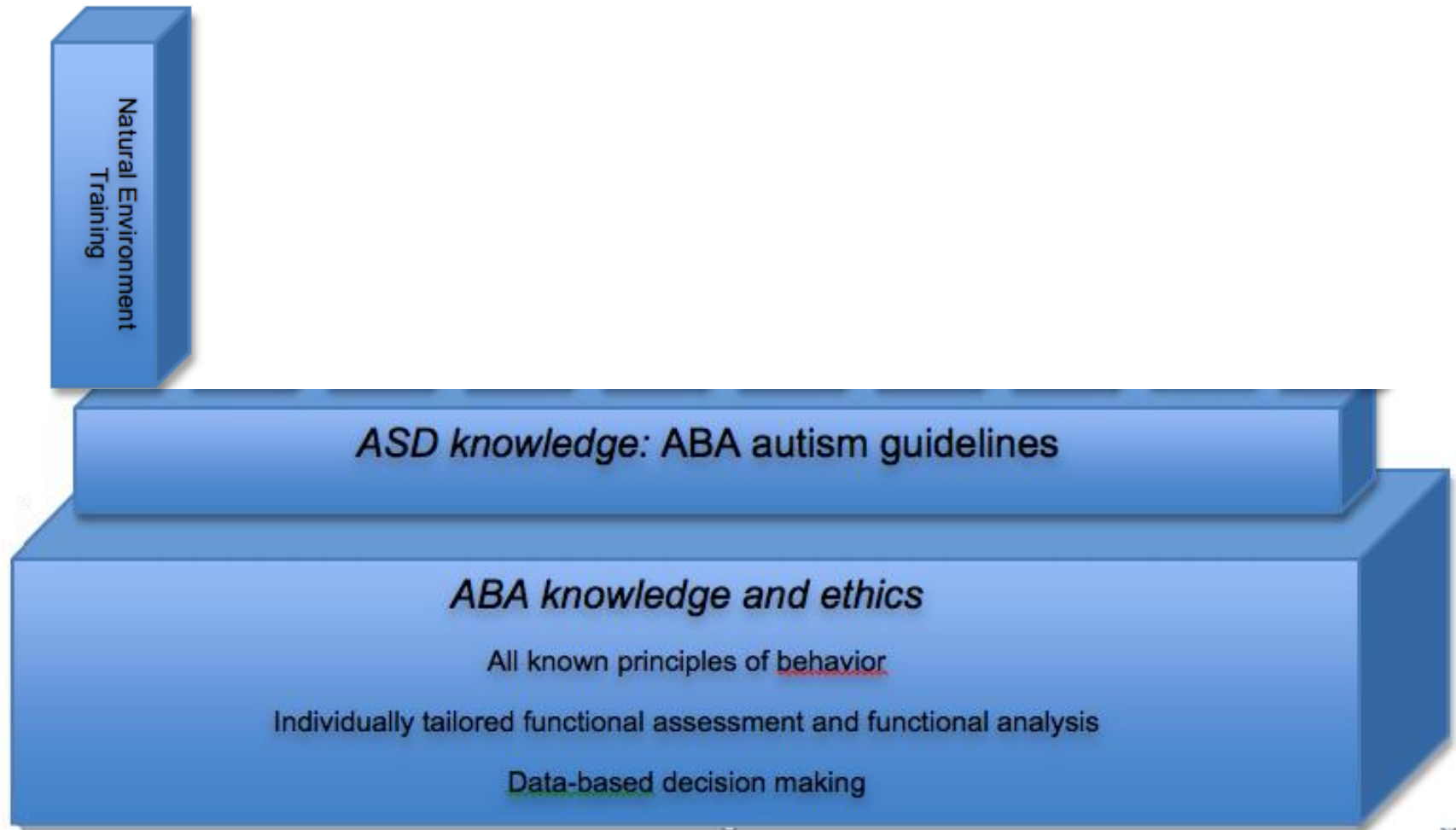
Person/Child-Centred

# Applied behaviour analysis for ASD



Person/Child-Centred

# Applied behaviour analysis for ASD

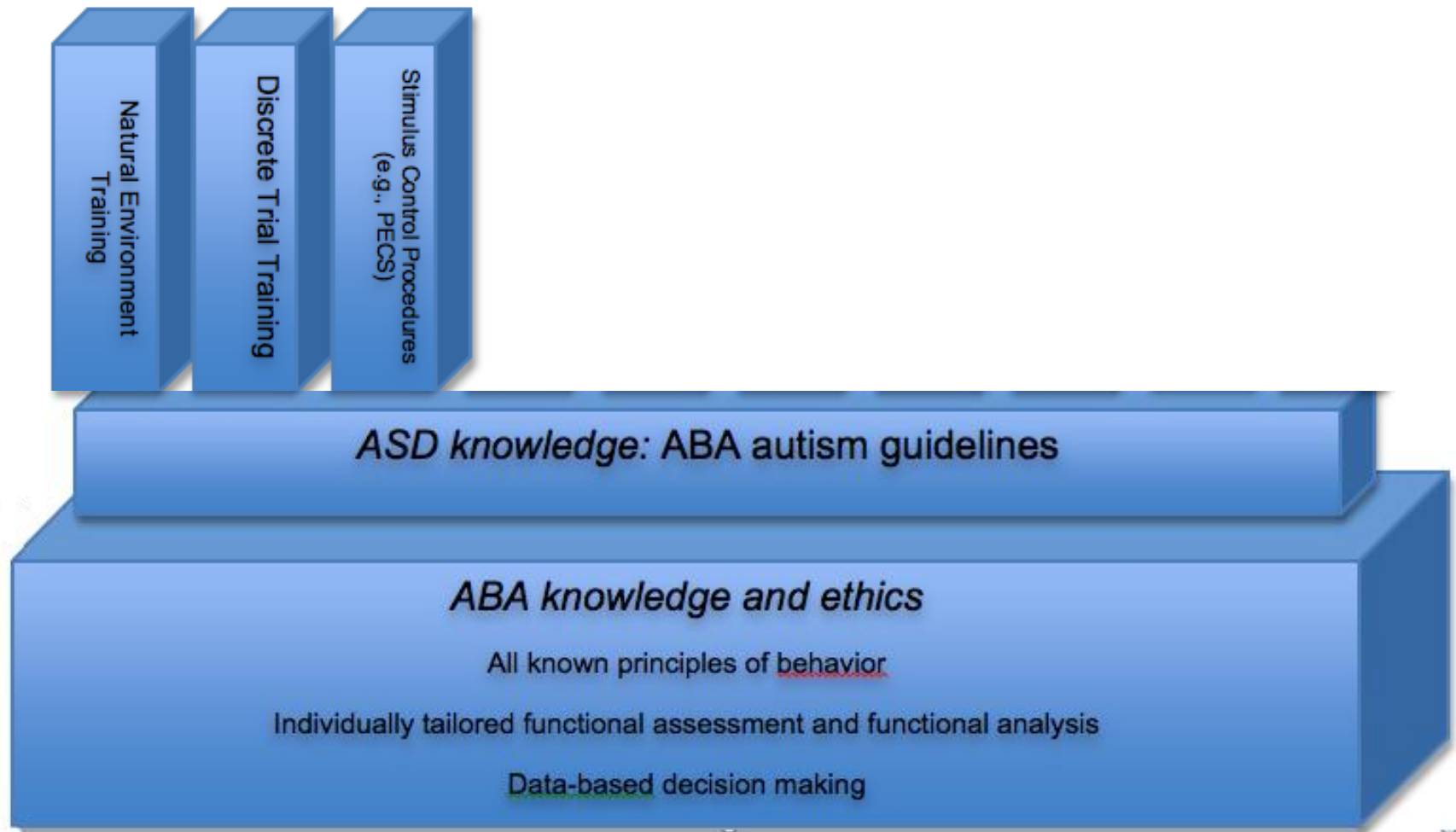


# Applied behaviour analysis for ASD

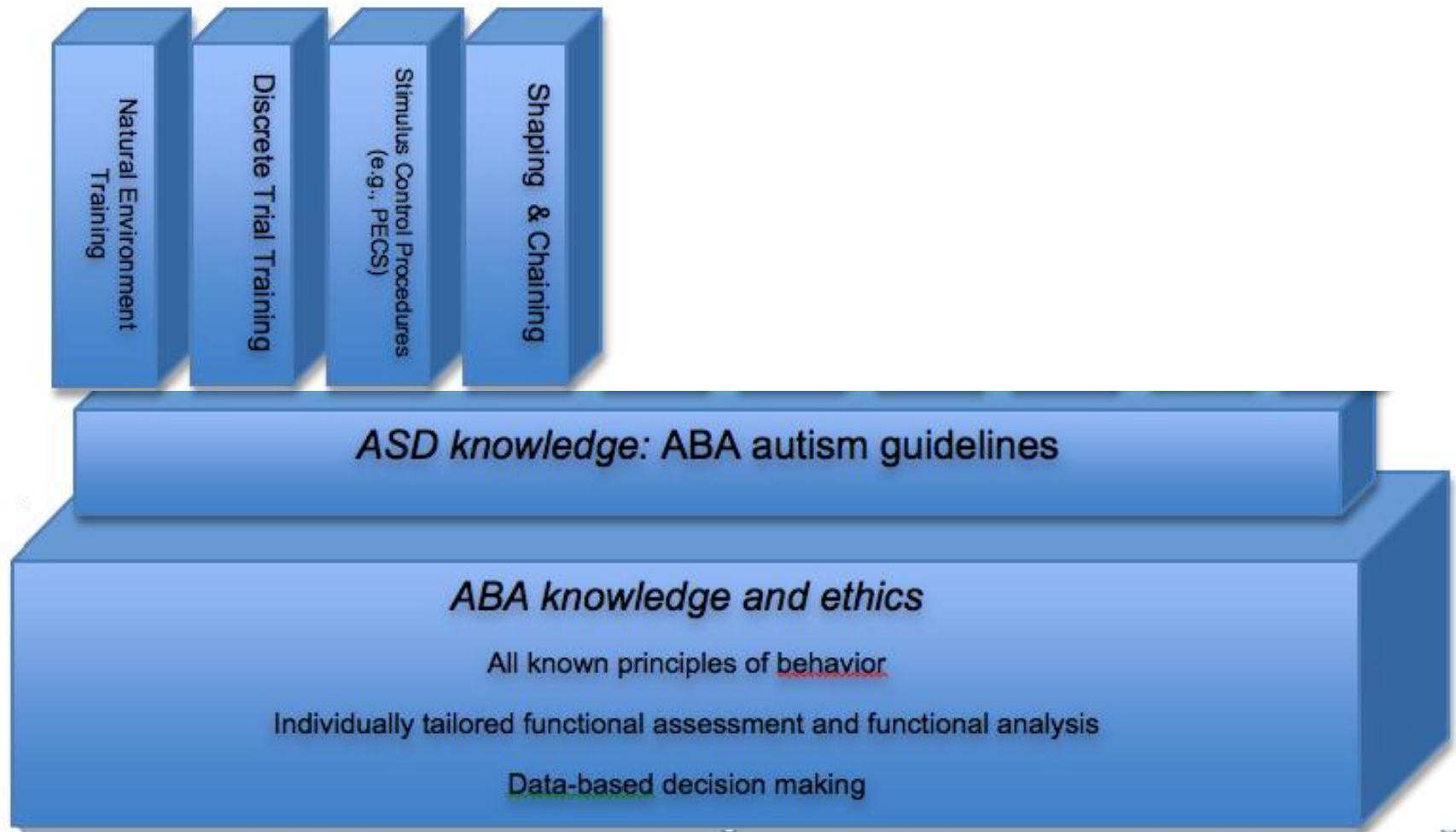




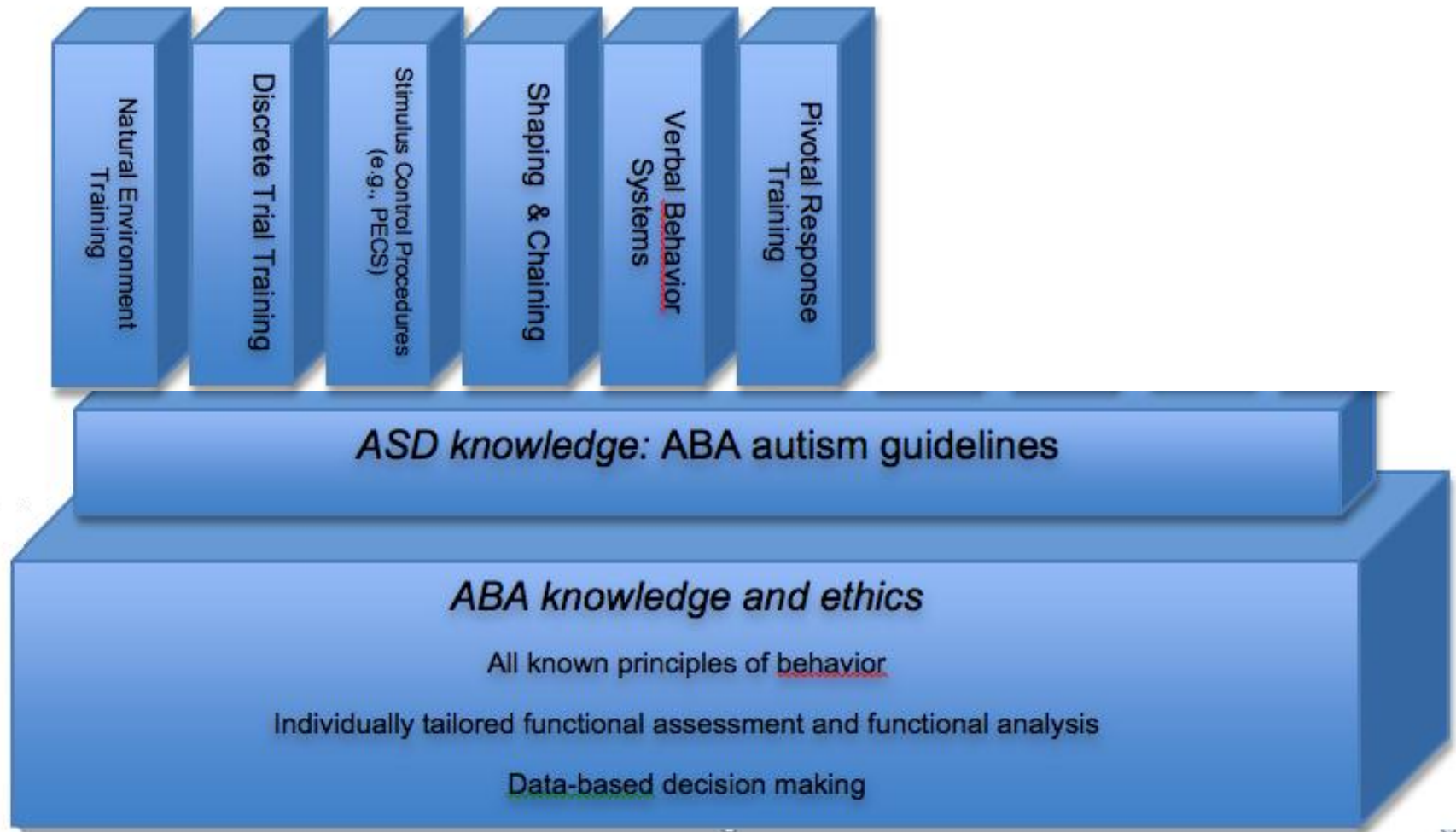
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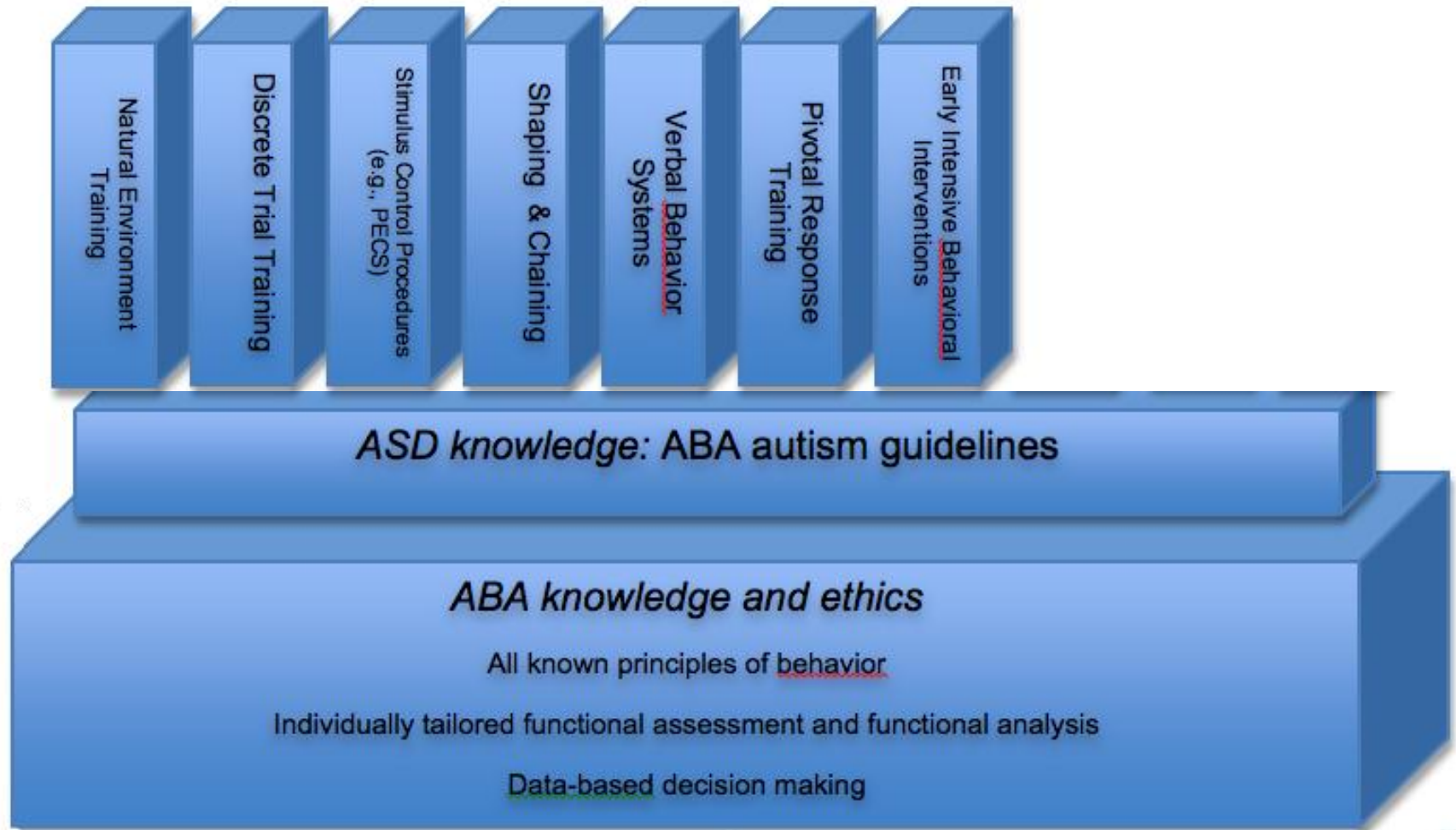
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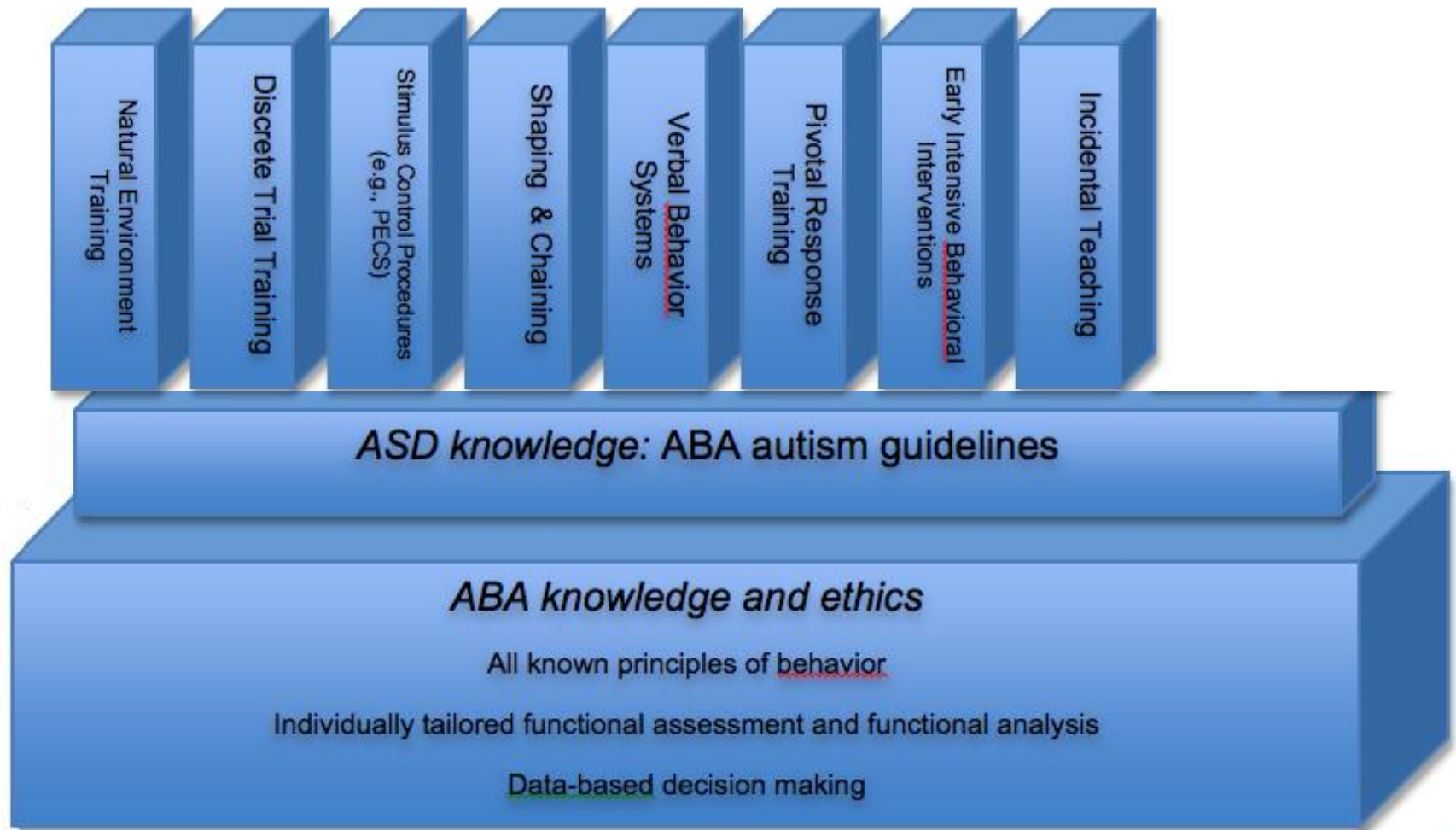
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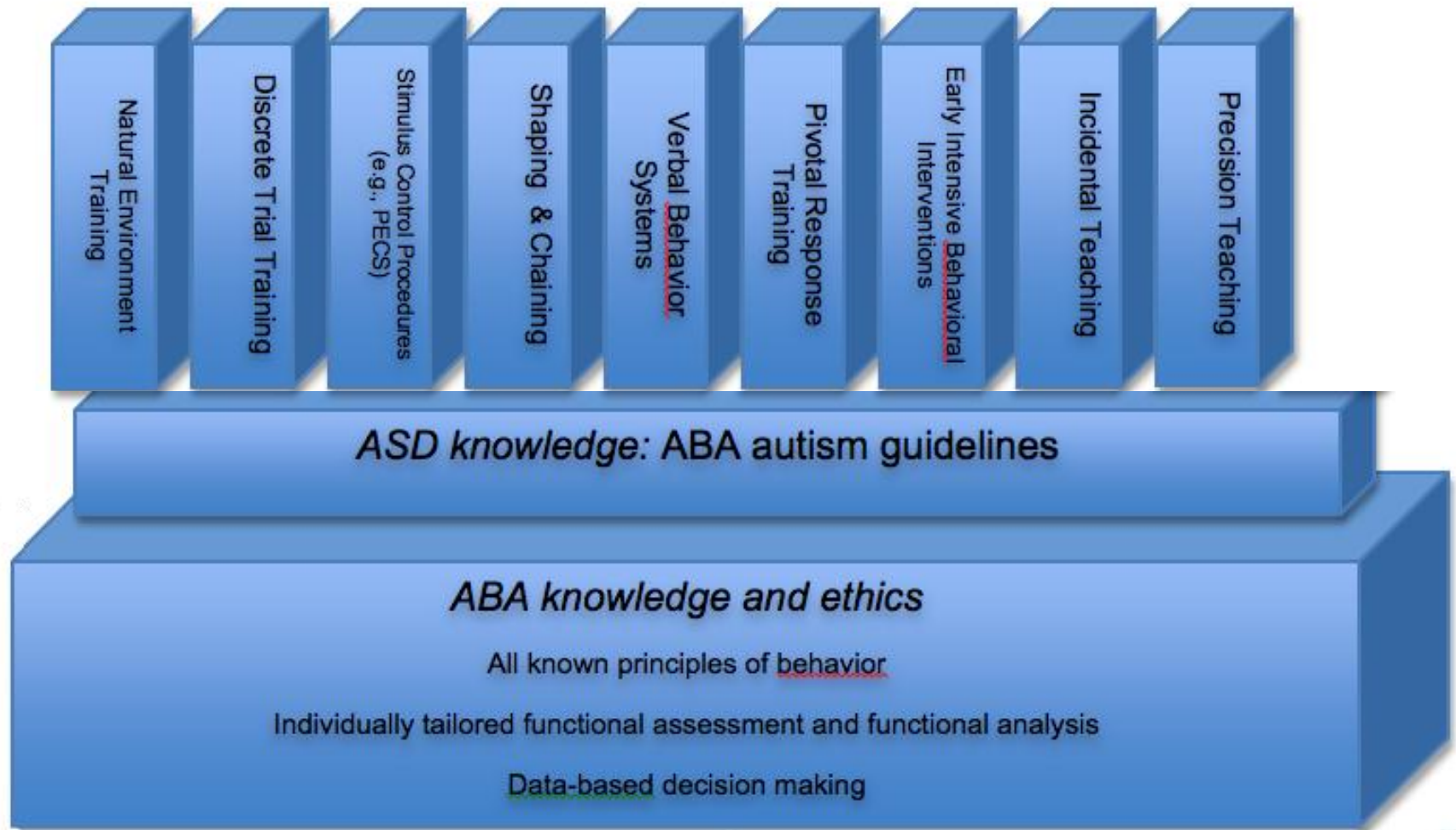


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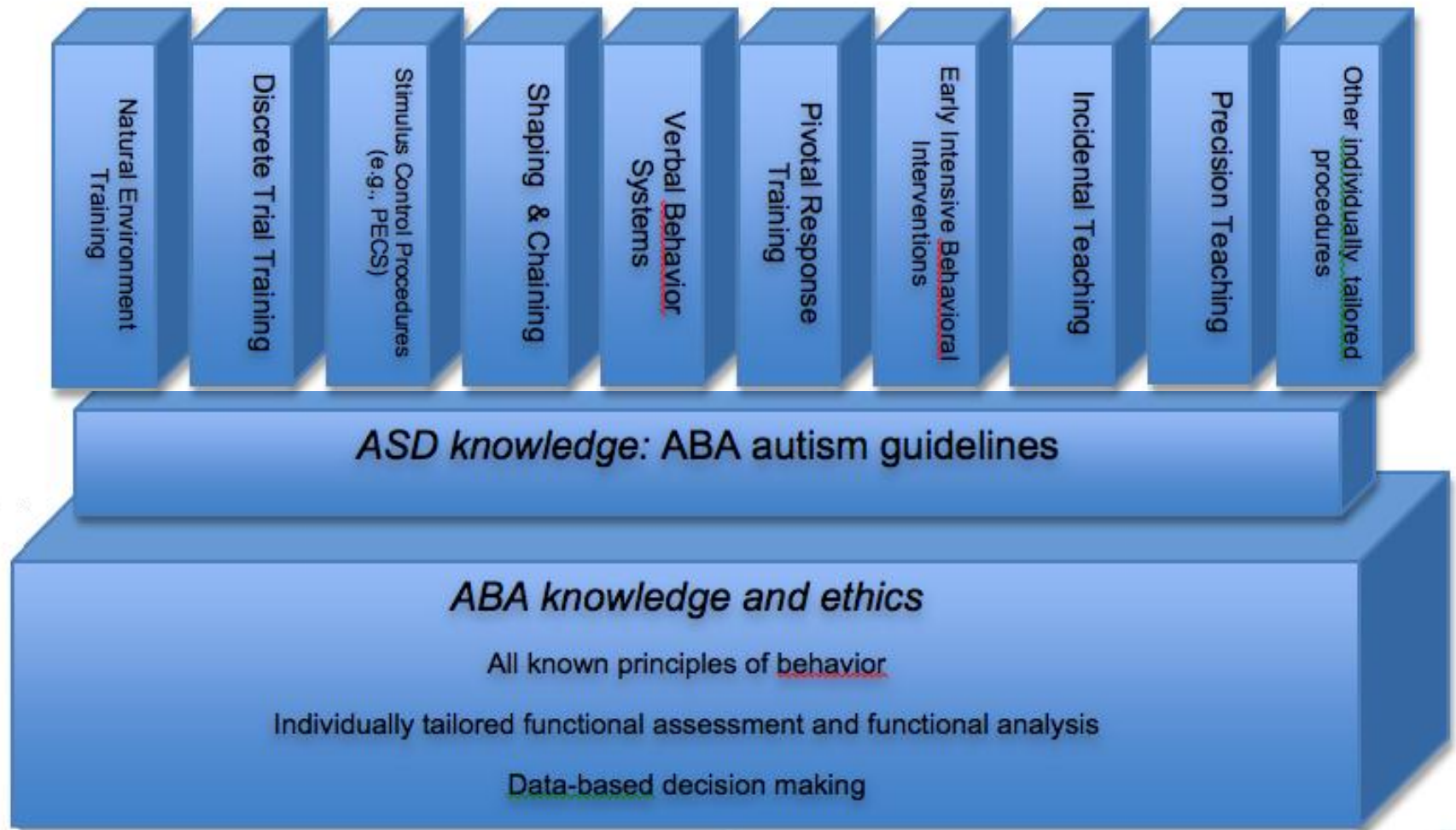




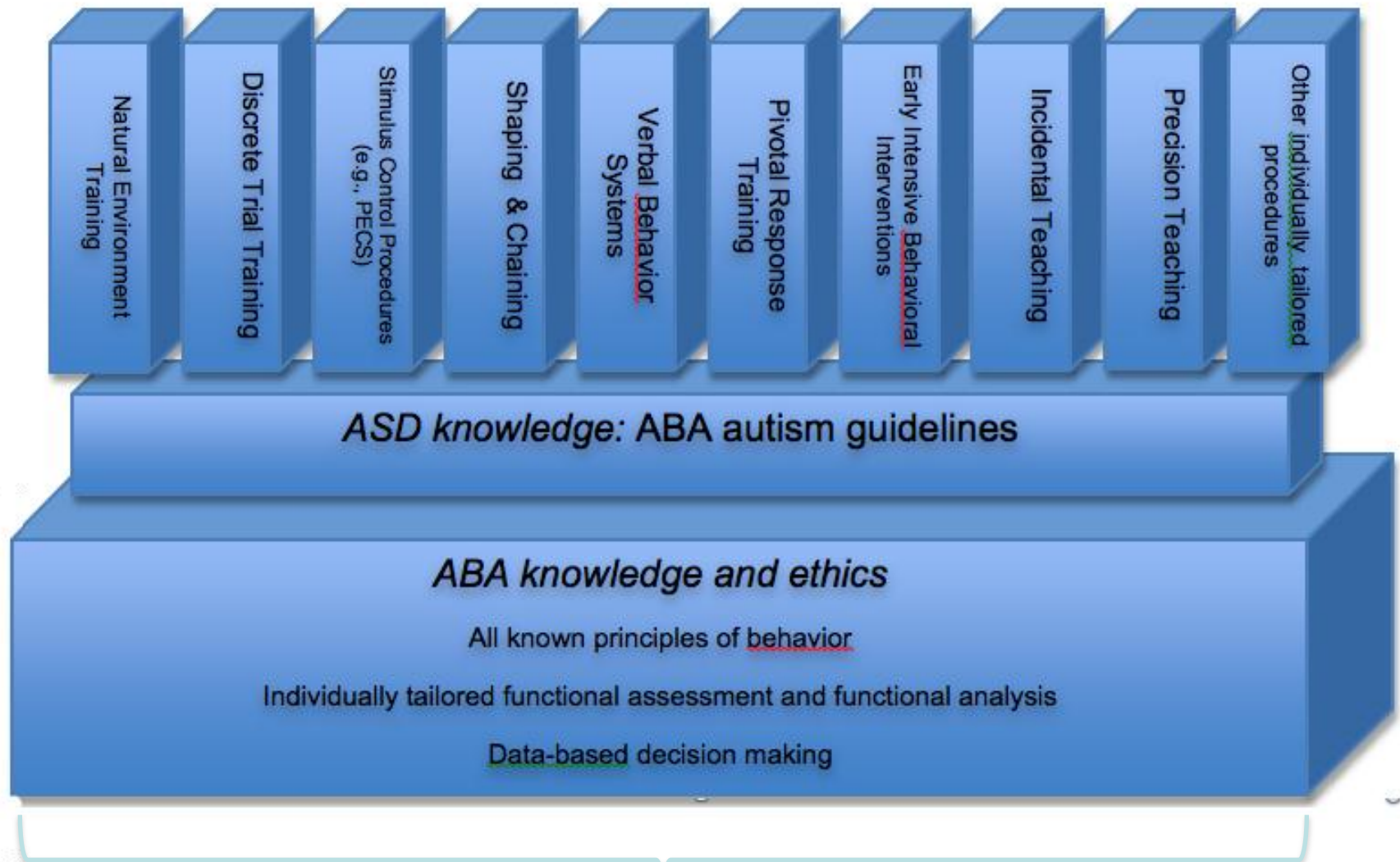
# Applied behaviour analysis for ASD



# Applied behaviour analysis for ASD



# Applied behaviour analysis for ASD



## 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

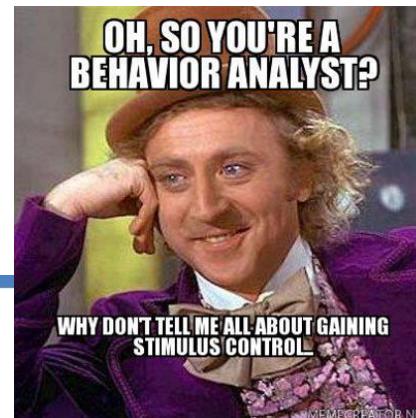
Reduced stress levels





# Research Bias

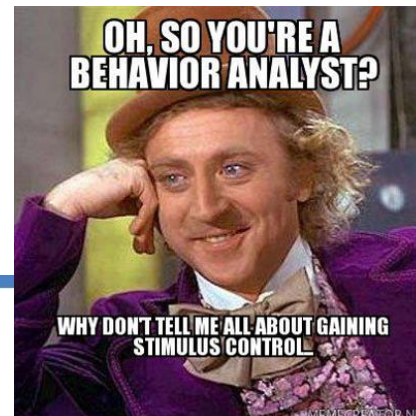
Who should conduct Dental Research?





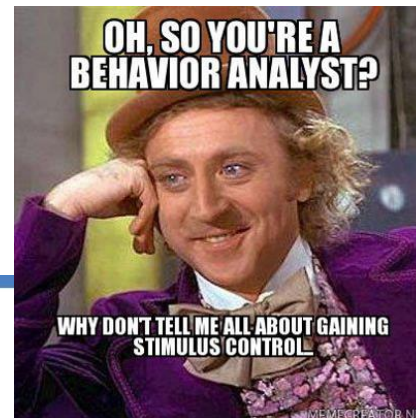
# Research Bias

Who should conduct Meteorological Research?



# Research Bias

Who should conduct Behaviour Analysis Research?



Nothing about us  
Without us!



# Board Certified Behavior Analyst® (BCBA®)

NEW REQUIREMENTS		
Research Methods in Behavior Analysis	Ethical and Professional Conduct	45 hrs
	Concepts and Principles of Behavior Analysis	45 hrs
	Measurement (including Data Analysis)	25 hrs
	Experimental Design	20 hrs
Applied Behavior Analysis	Identification of the Problem & Assessment	30 hrs
	Fundamental Elements of Behavior Change & Specific Behavior Change Procedures	45 hrs
	Intervention & Behavior Change Considerations	10 hrs
	Behavior Change Systems	10 hrs
	Implementation, Management and Supervision	10 hrs
	Discretionary	30 hrs
<b>TOTAL</b>		<b>270 hrs</b>

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

# Board Certified assistant Behavior Analyst® (BCaBA®)

NEW REQUIREMENTS		
	Ethical and Professional Conduct	15 hrs
	Concepts and Principles of Behavior Analysis	45 hrs
	Measurement (including Data Analysis)	10 hrs
Research Methods in Behavior Analysis	Experimental Design	5 hrs
Applied Behavior Analysis	Identification of the Problem & Assessment	30 hrs
	Fundamental Elements of Behavior Change & Specific Behavior Change Procedures	45 hrs
	Behavior Change Systems	5 hrs
	Intervention & Behavior Change Considerations	5 hrs
	Implementation, Management and Supervision	5 hrs
	Discretionary	15 hrs
TOTAL		180hrs

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](http://www.bacb.com)

# Registered Behavior Technician® (RBT®)

## 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](http://www.bacb.com)



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- Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose – response meta-analysis of multiple outcomes. *Clinical Psychology Review*, 30, 387 – 399.





# OVERCOMING BARRIERS. ACHIEVING POTENTIAL.

Education for transformation

Dillenburger, K. (2012) Autism Spectrum Disorder: Evidence-based interventions. *National Association of Primary Care (NAPC) Review*, Spring/Summer, 134-135.

Dillenburger, K. (2011). The Emperor's new clothes: Eclecticism in autism treatment. *Research in Autism Spectrum Disorders*, 5 , 1119– 1128.

Dillenburger, K. & Keenan, M. (2009). None of the As in ABA stands for autism: Dispelling the myths. *Journal of Intellectual & Developmental Disability*. 34, 193-195. More [www.qub.ac.uk/cba](http://www.qub.ac.uk/cba)





Northern Ireland  
Assembly



The Open  
University



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