



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



Evidence and Policy: How to help families of children diagnosed with autism in Northern Ireland

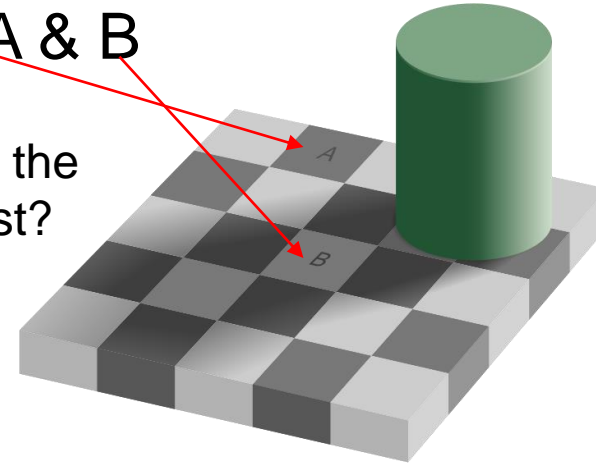
Prof. Mickey Keenan FBPSS BCBA-D

School of Psychology
Ulster University

Perceptions: an Illusion

Look at A & B

Which is the
brightest?



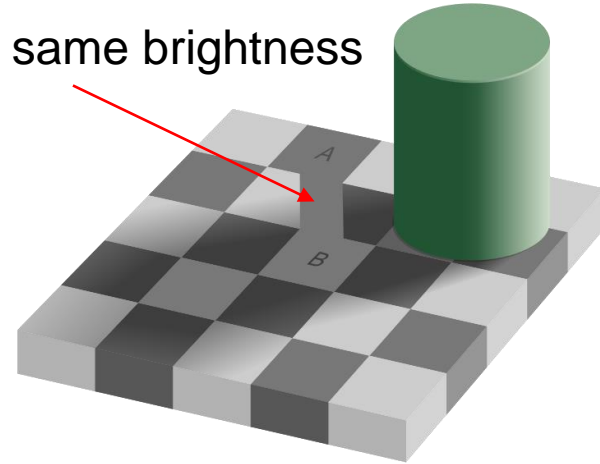
Perceptions: an Illusion

Simple lesson: It is possible to be deceived. They are the same brightness

Catherine Maurice (1999), mother and author of influential book on ABA 'Let me hear your voice', responds to the negative perceptions of ABA she encountered:

Local professionals who work with young children suggested to Task Group members that they would have grave reservations about being gradually, I began to understand ABA more and more. I started to understand what is young children to such an intense was: Not some dehumanizing control of people through a cynical manipulation of rewards and punishments, but rather the light of scientific exploration brought to bear upon behavior, and upon learning.

There is NO supporting research evidence to justify this inclusion



Decisions facing a Minister

How to choose between so many interventions?

Intervention 1

Intervention 2

Intervention 3

Intervention 4

Intervention 5....

Minister for Education, 2009

Applied Behaviour Analysis (ABA) is one of many commercially available interventions for children with autism

The Task Group on Autism concluded that “Interventions should be child-centred rather than method centred, and should address the observed and unique needs of the child.” I continue to accept this view and, therefore, do not promote one type of intervention over another.

CAITRÍONA RUANE MLA (2010)

Intervention 1

Intervention 2

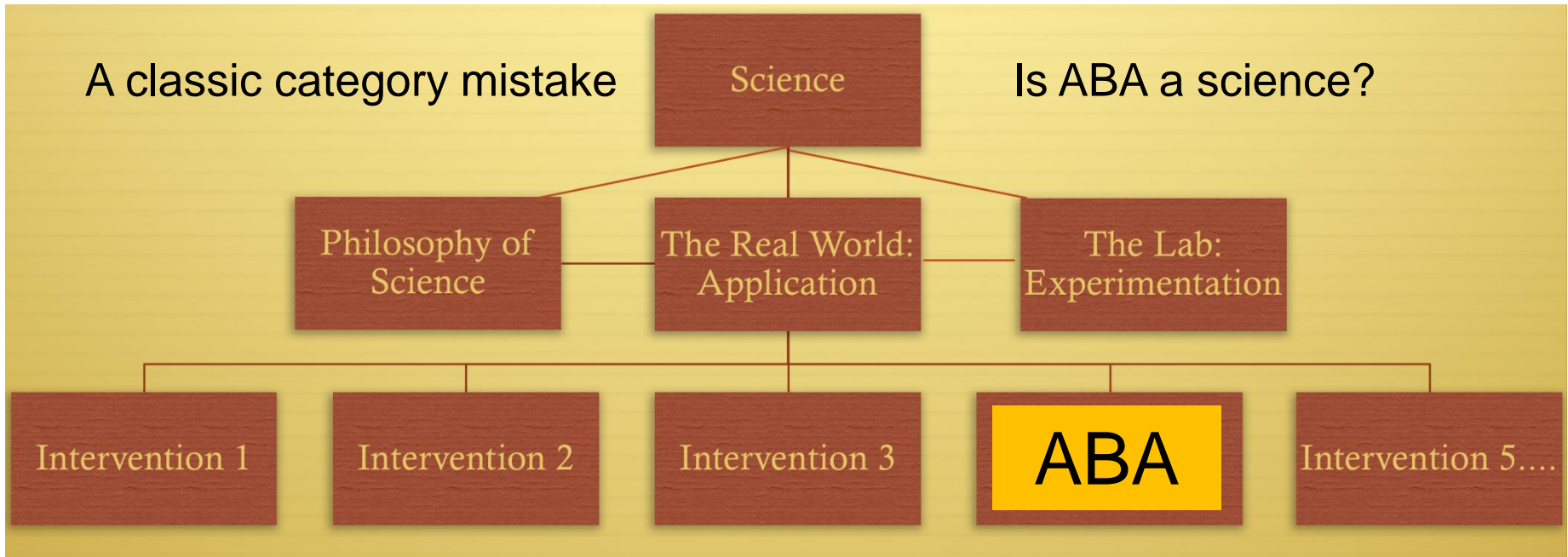
Intervention 3

ABA

Intervention 5....

Minister for Education, 2009

Extremely serious **ETHICAL** questions about competency of advisers
available interventions for children with autism



Although there are **several journals** devoted to the science of behaviour analysis, the two primary journals are the **Journal of the Experimental Analysis of Behavior** and the **Journal of Applied Behavior Analysis**. Both are highly rigorous journals with strong citation indices. But all of this is well established fact and what surprises me is that any educated person would question it. (Patrick Friman, PhD, Clinical Professor of Pediatrics, Past President of the Association for Behavior Analysis International)

Psychologists and other serious mental health professionals in the UK
Extremely serious ETHICAL questions about competence of advisers
are not raised by professional standards outside the UK

Competence in a Science

- Practice within the boundaries of their competence.
- Engage in Continued Professional Development.

British Psychological Society, Ethical Code of Practice

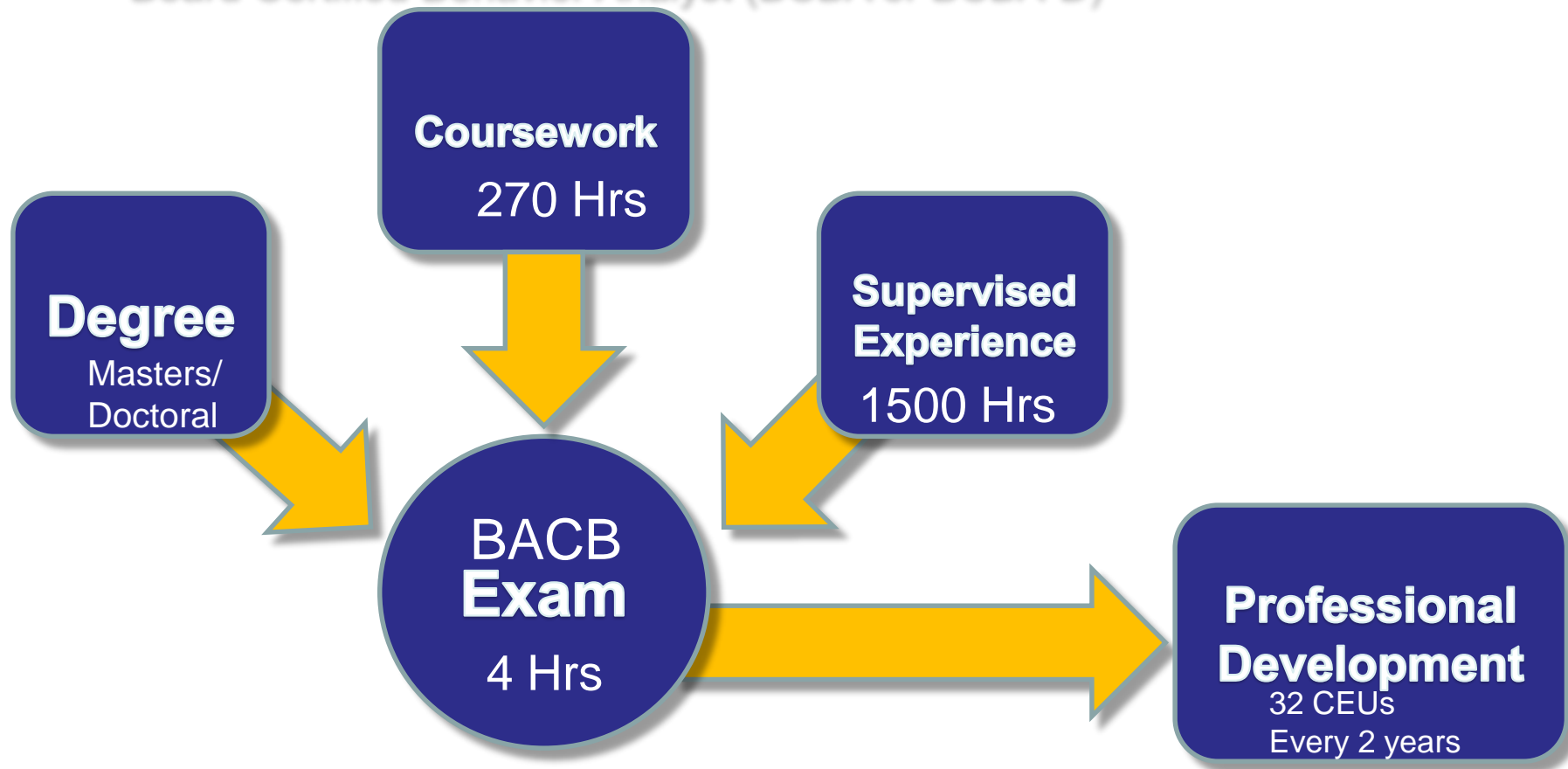
As a general rule, in matters concerning Physics, the Institute of Physics in Ireland would seek to have appropriately qualified physicists represented on any review panel which might be reporting on 'findings from Physics'.

Institute of Physics in Ireland

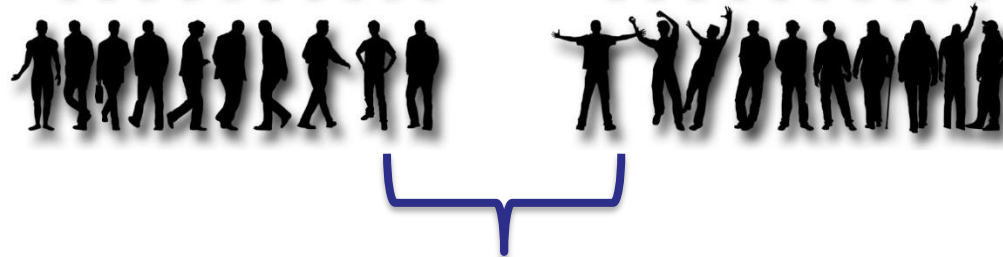
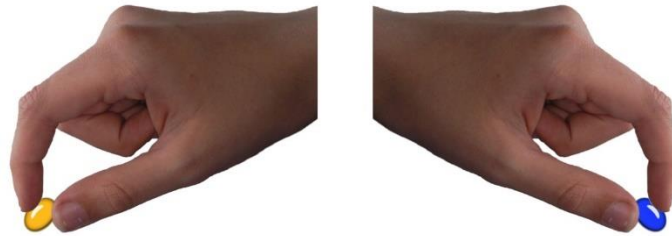


Training standards in Applied Behaviour Analysis (www.bacb.com)

Board Certified Behavior Analyst (BCBA or BCBA-D)

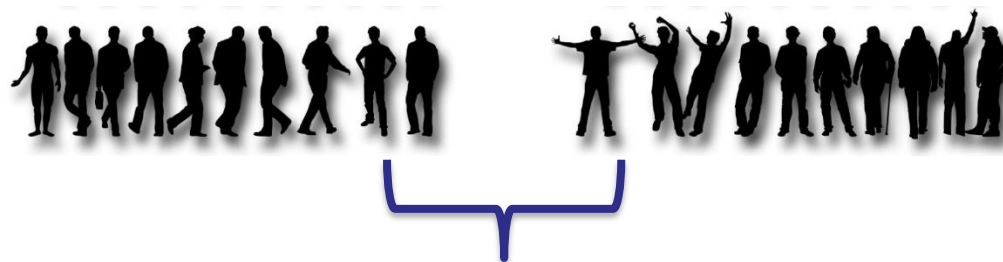
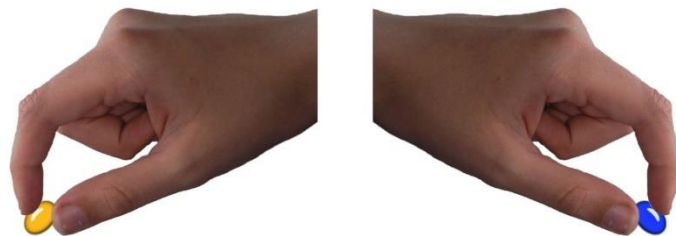


Randomised Control Trial (RCT): Gold Standard



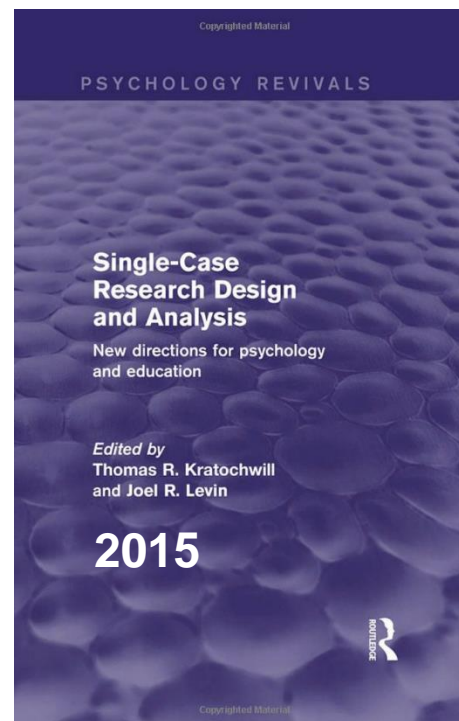
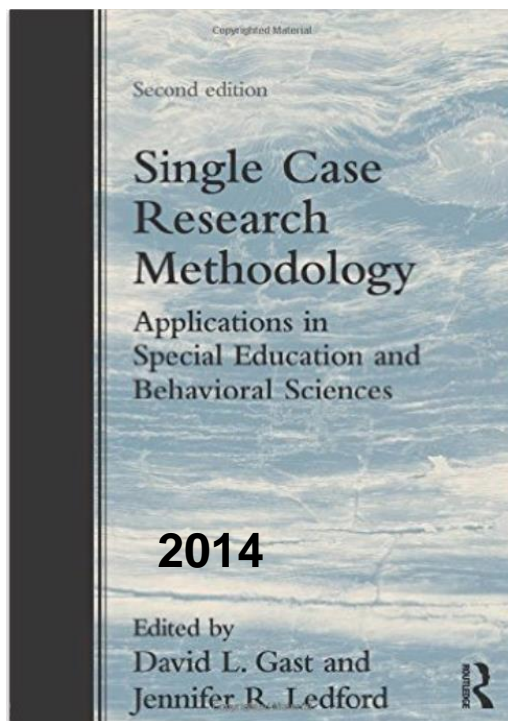
Results guide policy decisions

Randomised Control Trial (RCT): Gold Standard



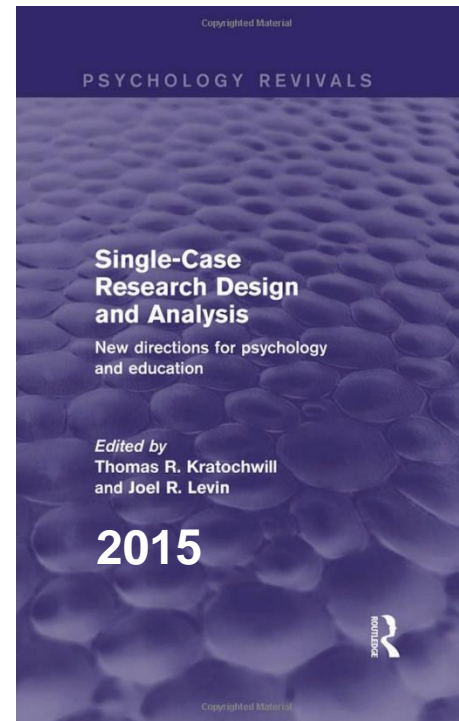
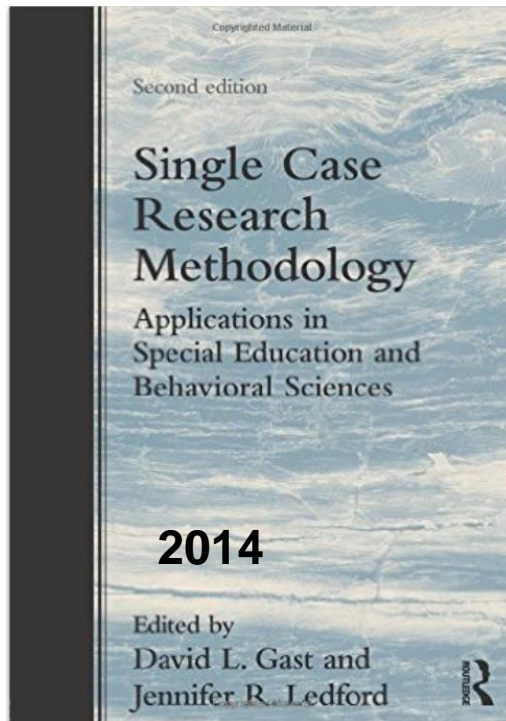
What is a scientific study without random assignment to groups?
 (“**Giving science a bad name**” Marie-Louise Hughes, 2008)

Randomised Control Trial (RCT): Gold Standard



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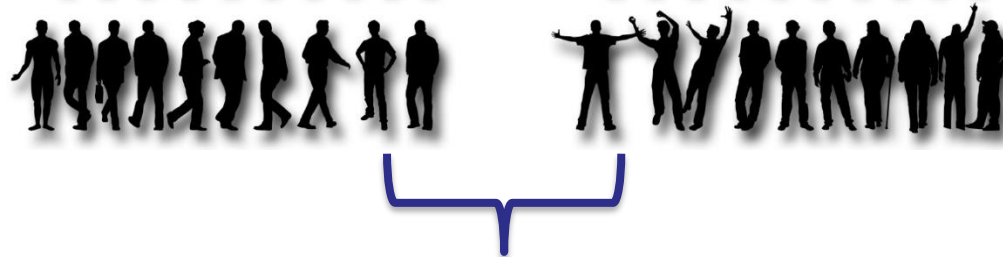
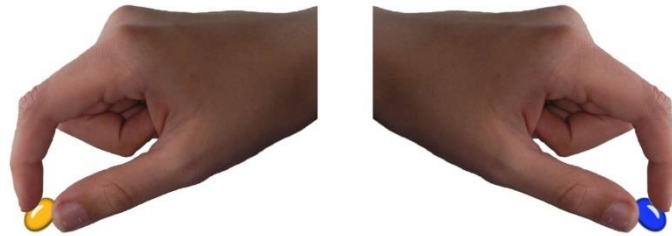
Randomised Control Trial (RCT): Gold Standard



What is a scientific study without random assignment to groups?
(**BPS Ethical code**: Engage in Continued Professional Development)

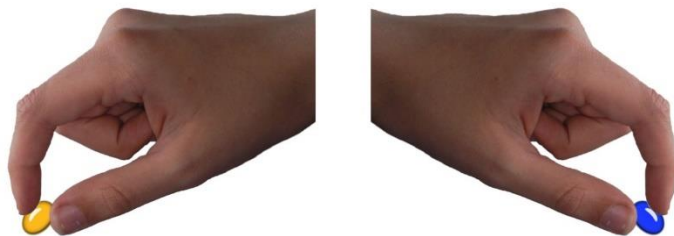


Randomised Control Trial (RCT): Gold Standard

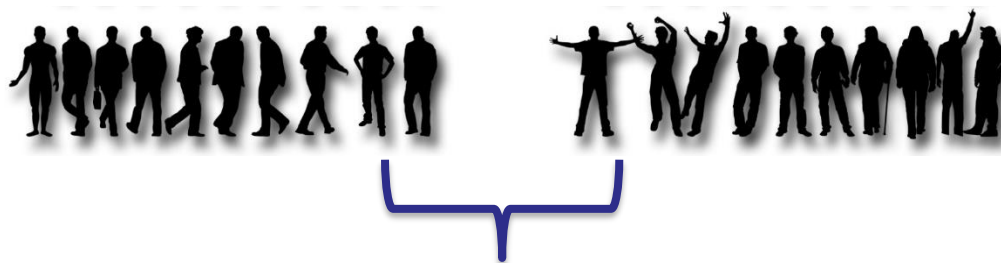


Don't use parachutes because there are no RCTs!

Randomised Control Trial (RCT): Gold Standard

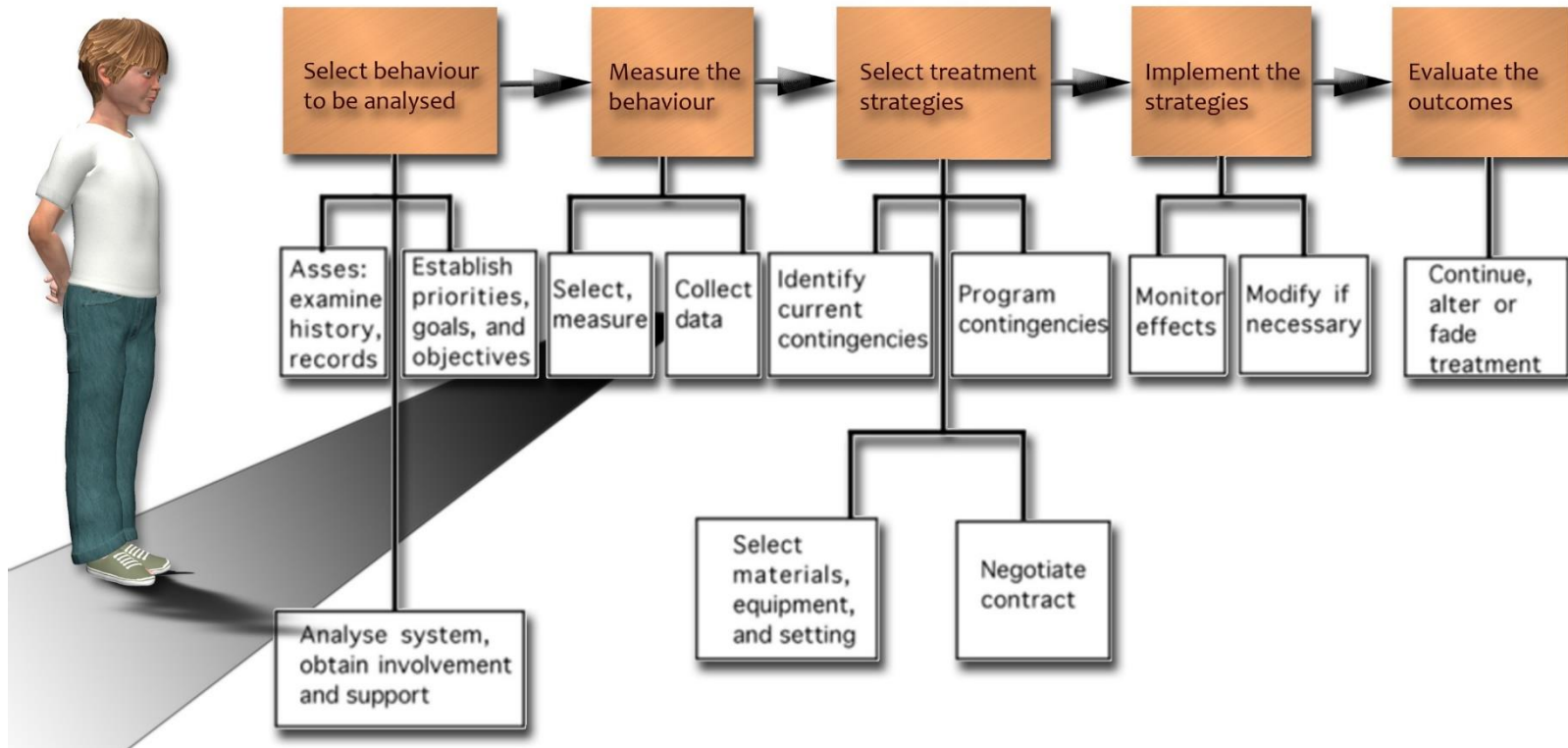


Clinical Psychology
Educational Psychology
Speech Therapy
Occupational Therapy
Applied Behaviour Analysis



Don't use these disciplines because there are no RCTs!

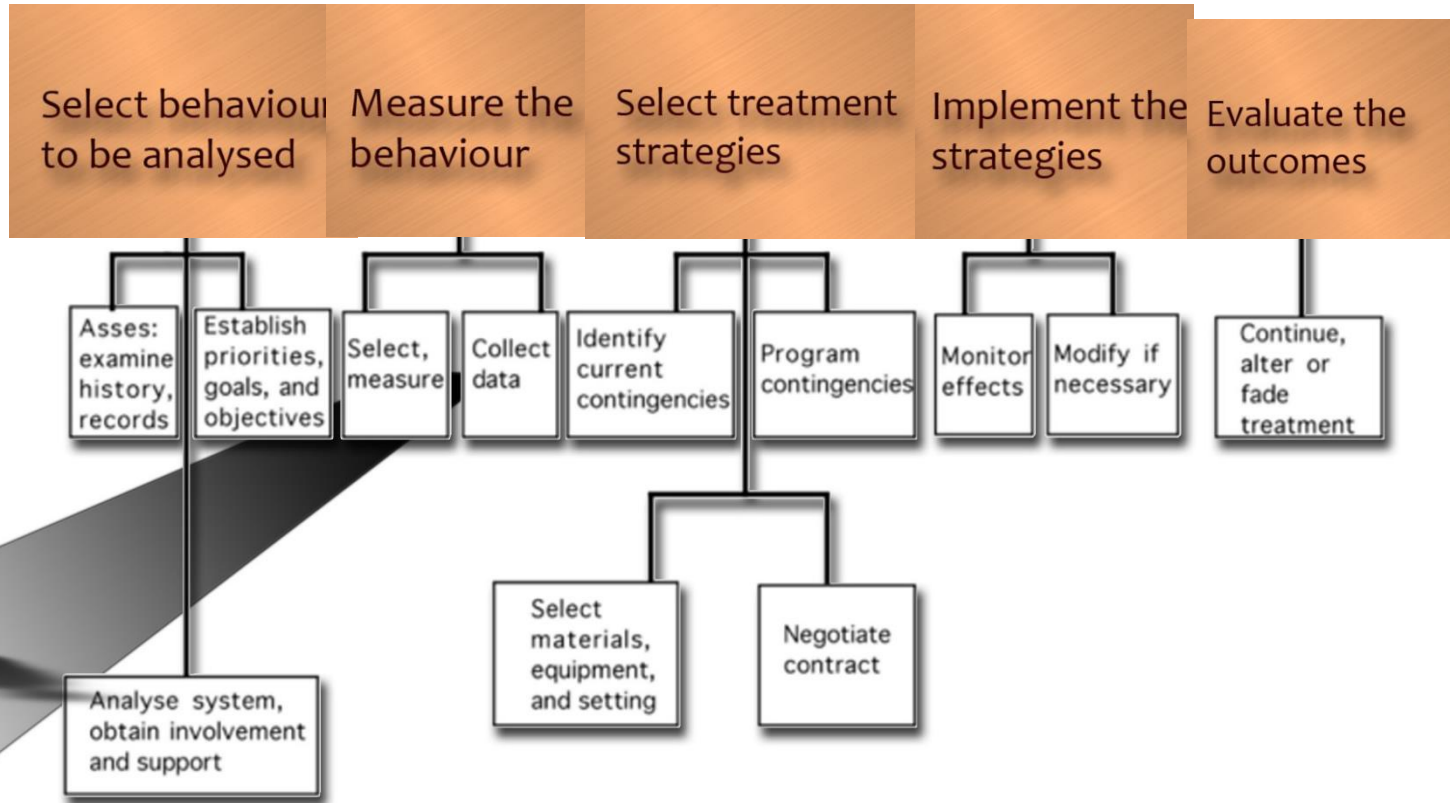
Evidence-based practice: Scientific Method Science without groups Tailored to meet the needs of the individual



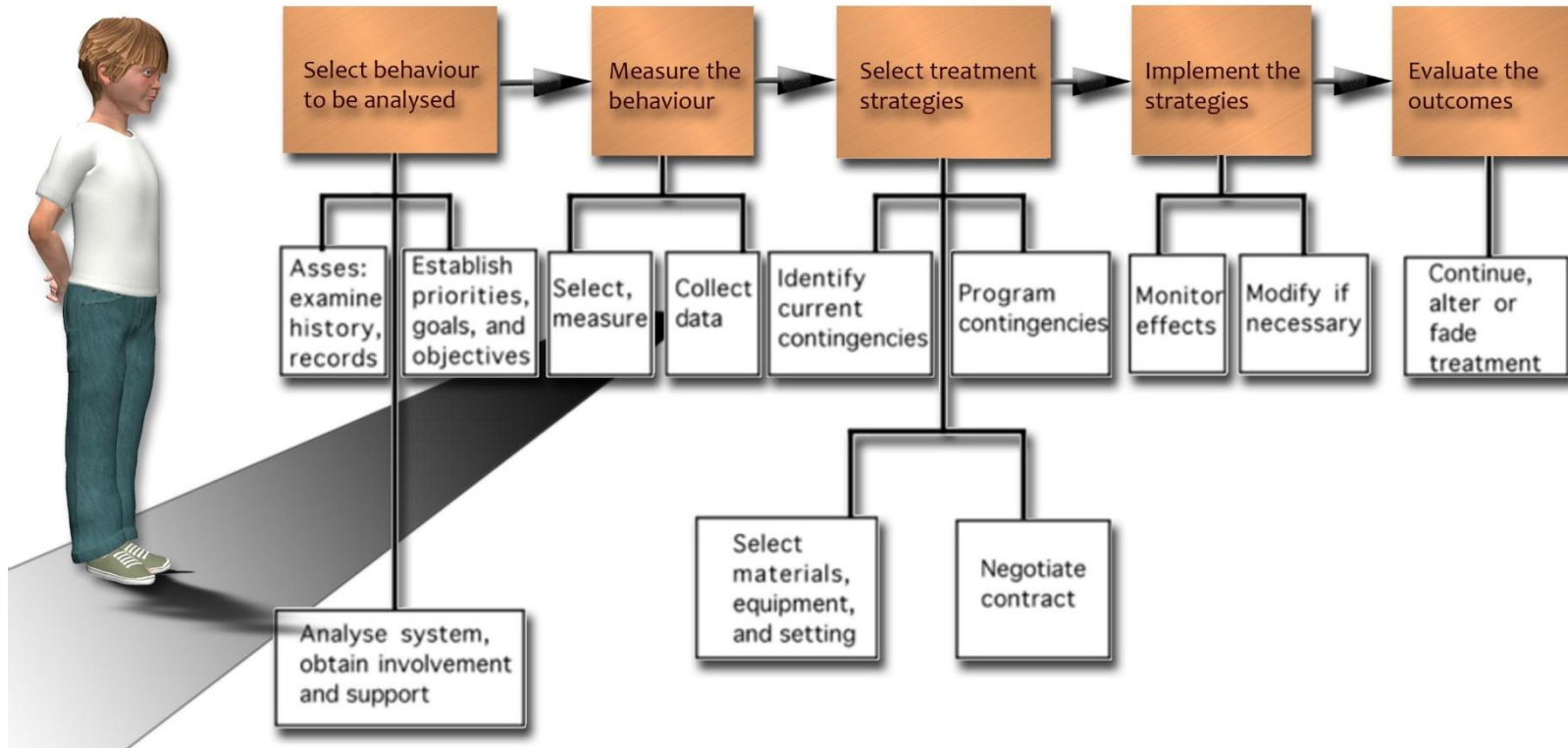
Scientific Method

Tailored to meet the needs of the individual

Controversial? Controversial? Controversial? Controversial? Controversial?



The dominant perspective in N. Ireland is that ABA is controversial. However, the term 'Controversial' should be reserved for the consequences of demonising a science



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Support for Applied Behaviour Analysis

American Association on Intellectual and Developmental Disabilities “highly recommended” (highest rating)

National Institute of Mental Health
The National Academies Press
Association for Science in Autism Treatment
Autism Speaks
Organization For Autism Research

} ABA-based procedures are highly effective

{ Surgeon General of the United States.....

“Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”

{ New York State Department of Health

{ Maine Administrators of Services for Children with Disabilities

{ U.S. Dept. of Defense

Current Opinion in Psychiatry

“Interventions based on applied behavior analysis have the strongest empirical basis, although there is some evidence that other therapies have promise.” (Sturmey, 2002)

Pediatrics

“The most efficacious psychosocial treatment for autism is applied behavior analysis...” (Lilienfeld, 2005)

Supreme Court of British Columbia (2000)

“...It is beyond debate that the appropriate treatment is ABA or early intensive behavioural intervention.”



National Standards Project – 2009

(<http://www.nationalautismcenter.org/>)
Largest review ever conducted

The overwhelming majority of interventions were developed in the **behavioural** literature.

Office of Personnel Management



Benefits Review Panel concluded:

There is now sufficient evidence to categorise ABA as medical therapy rather than purely educational (U.S. Office of Personnel Management , 2012)

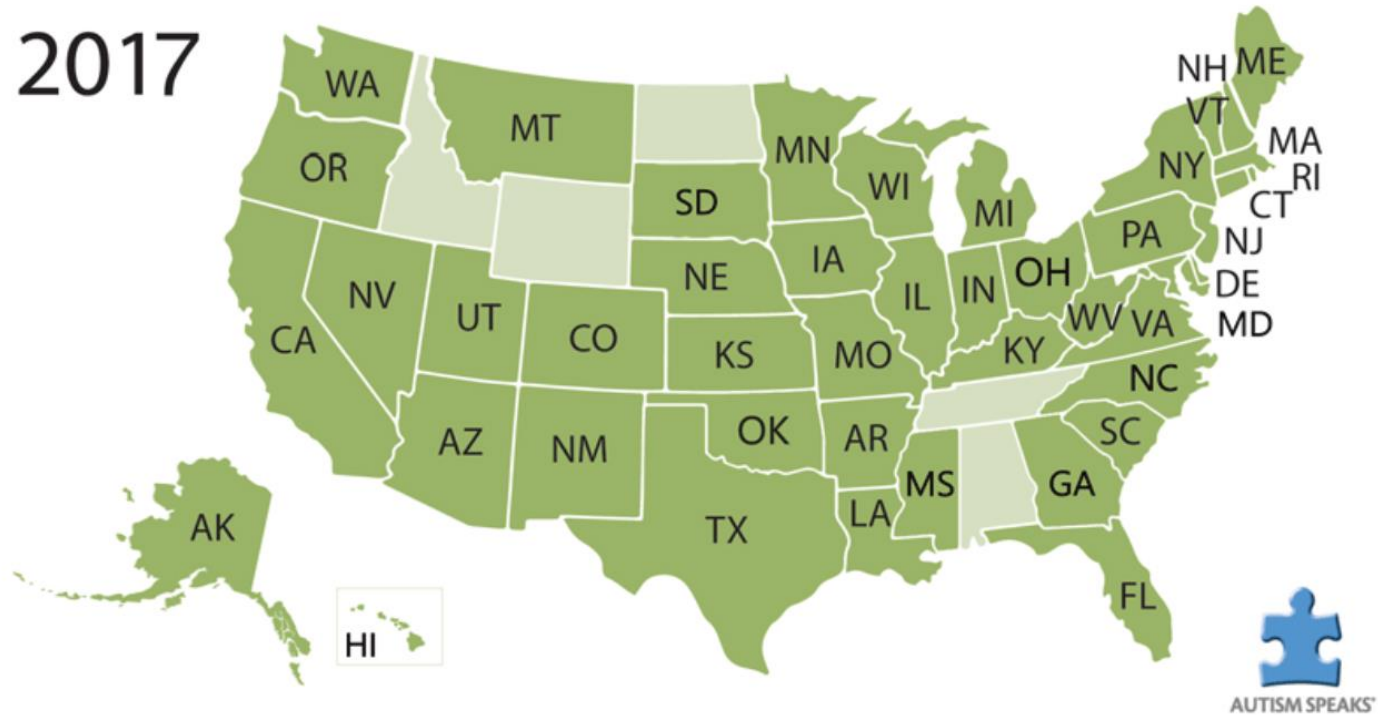
American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

In Capitol Hill testimony, the 60,000-member American Academy of Pediatrics publicly endorsed the use of ABA treatments (AAP, June 2012)

2017



GREEN - States (45 + District of Columbia; US Virgin Islands) with enacted autism insurance reform laws

These laws ensure parents can get access to ABA



Psychologists and other government advisers in the UK
are not trained to international standards in ABA

The National Institute for Clinical Excellence (NICE), in their response to the consultation for guidelines for the management of children with autism concluded the following:

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



PARENTS SPEAK ABOUT ABA



<https://tinyurl.com/zsvjll5>

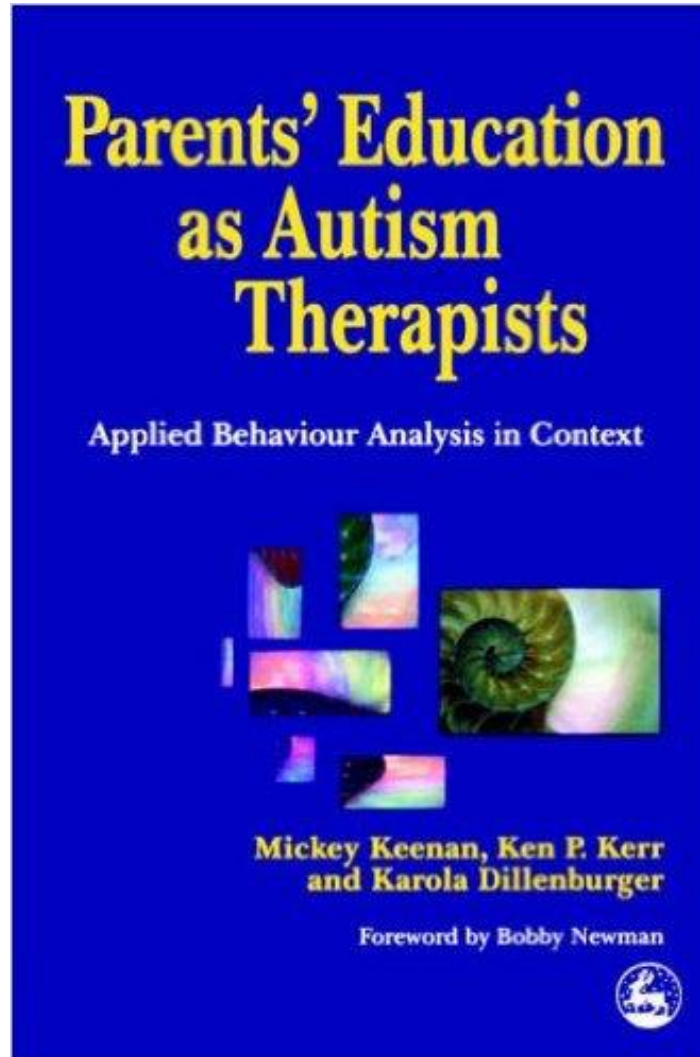


<https://tinyurl.com/jaw6xnl>



First book in Europe teaching ABA to parents.

Translated into Japanese and German, with Greek translation underway



Written with help of parents from PEAT charity.

The first charity in Ireland whose mission was to promote ABA.

Parents given practical skills and not just training in autism awareness

For over 20 years has received NO government support yet it receives referrals from numerous statutory bodies and other charities who do receive financial support.



European funding to develop online multimedia training in ABA in 8 languages

The screenshot shows the website www.simplestepsautism.com in a browser window. The browser's address bar and tabs are visible at the top. Below the browser window, the website's navigation menu includes links for Home, Why Simple Steps?, About Autism, Testimonials, Contact Us, and Purchase Now. A 'Purchase Now' button with a shopping cart icon is also present. The main content area features the 'simplesteps autism' logo and the tagline 'The Online Teaching Platform for the treatment of Autism', with a sub-tagline 'Simple but effective tools based on the proven science of ABA'. A Facebook icon is located to the right of the tagline. Below this, a 'Video Tour' section displays images of the program's materials and lists features: Animated Tutorials, Video Training, Measurable Results, Professional Advice, and Downloadable Resources. Three additional sections are visible: 'Get your FREE Resources!' with a link to a complete list, 'For Parents' with a link for more info, and 'For Professionals' with a link to get in touch.

Coping with Autism Spectrum Disorder in children – Simple Steps Autism Edition ABA

www.simplestepsautism.com

Mac sharing...echRepublic Prosocial Pr...tion – Home Behavior De...ntinuing Ed ► Challengi...s – YouTube Misrepresen...or Analysis Autism, Sibl...v – YouTube

Germany Denmark France Netherlands Norway Portugal Spain Sweden United Kingdom United States

Purchase Now

Home | Why Simple Steps? | About Autism | Testimonials | Contact Us | Purchase Now

Home | Login | Register

simplesteps autism

The Online Teaching Platform for the treatment of Autism

Simple but effective tools based on the proven science of ABA

Video Tour

Simple Steps Includes:

- Animated Tutorials
- Video Training
- Measurable Results
- Professional Advice
- Downloadable Resources and much more.

Get your FREE Resources!

Download Teaching Resources now.

Click here for the complete list...

Click for more info

For Parents

Support when you need it.

Click here for information on effective, easy to use & affordable tools.

Click for more info

For Professionals

Support families with interactive resources.

Click here for information on how you can help families in your area.

Get in touch



Major awards for founder of PEAT Charity

- 2002 Award for Promoting Equality of Opportunity. *The British Psychological Society*
- 2002/2003 Distinguished Community Fellowship. *Ulster University*
- 2005 Personal Achievement Award. *New York State Association for Behavior Analysis*
- 2006 *Elected Fellow of the British Psychological Society*
- 2008 Award for Public Service in Behavior Analysis.
the Society for Advancement in Behavior Analysis
- 2014 Michael Hemmingway award. Behavior Analyst Certification Board
- 2015 International Dissemination of Behavior Analysis Award
Society for Advancement in Behavior Analysis
- 2015 First International Advocacy Award. *Autism Speaks*



Politics in Science

From: Jendoubi, Christine [mailto:Christine.Jendoubi@dhsspsni.gov.uk]

Sent: 21 November 2012 15:37

To: McKenna, Hugh

Cc: Deazley, Peter

Subject: MCHPA and other things....

Autism Strategy Research Advisory Committee

Founder of PEAT Charity and University expert excluded

Hello Hugh

It was good to see you again at Hillsborough. A couple of things:



The other thing I was wanting to talk to you about was the Autism Strategy Research Advisory Committee. This committee has not got off the ground yet and I am intending to write to both yourselves and QUB to ask for a nominee to sit on it and I was wanting to take your mind on whom I should be writing to in both institutions. At UU should it be you or your replacement as Dean of Life and Health Sciences? I was hoping it would be you so that I could have a quiet word and ask what the chances are of your nominating Roy McConkey, whom the Committee Chair, Arlene Cassidy, would very much welcome, as you can guess, as well as ourselves....

I asked Wendy who your equivalent was in Queen's and she suggested a couple of names but thought I'd be better asking you directly.

Much appreciated!

Christine Jendoubi (Mrs)

Director, Mental Health, Disability and Older People Policy | Department of Health, Social Services & Public Safety | Room C4.1, Castle Buildings, Stormont Estate, BELFAST BT4 3SQ Tel: (028) 90522388 (Dialnet 22388) | Blackberry: 07870509576 | Fax: (028) 90520574

Autism Strategy Document & Autism Action Plan

None of the wide-ranging University autism training programs or research was included in the **Autism Strategy** document or in the **Autism Action Plan**. In fact, the only mention of a university was in one very brief sentence related to widening participation of students with autism at Ulster University; QUB is not mentioned at all!

CEO of AutismNI

Obtained by parents under the
Freedom of Information Act



Politics in Science



Petitioning Chair of Autism Strategy Group Maura Briscoe and 2 others

Provide the choice of ABA-based interventions for children with ASD in Northern Ireland.

 Louise O'Neill
belfast, United Kingdom

ABA (Applied Behaviour Analysis) is not a 'treatment' for autism, but the scientific discipline from which principles of behaviour are uncovered which can give both children and adults new skills and ways of engaging with others. It's perhaps best known in working with children with autism,

2,931 signatures from around the world.

AutismNI refused to sign the petition.

Despite requests, the CEO declined to give a public presentation to explain this position to students studying ABA.

Politics in Science

Health Minister invited to a meeting at Autism Speaks headquarters in New York on 23rd Oct, 2013.

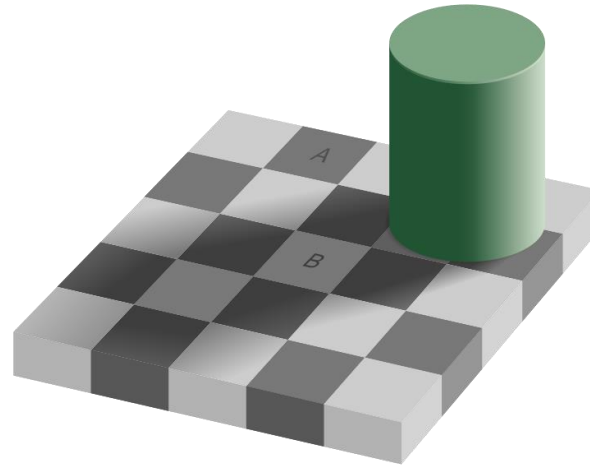
Response to a Freedom of Information Request for a copy of the minutes: **None are available.**



*Health Minister
N. Ireland*

*Vice President, State
Government Affairs,
Autism Speaks*

When illusion transforms into prejudice: Implications for Policy?



A ***prejudice*** is a prejudgement: i.e., a preconceived belief, opinion, or judgment made without ascertaining the facts of a case.

Institutional Discrimination refers to unequal treatment that is entrenched in basic social institutions resulting in advantaging one group over another

<http://www.urbanministry.org/wiki/prejudice>



Northern Ireland
Assembly



Queen's University
Belfast



The Open
University



Ulster
University

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