



A SPECTRUM OF HARMFUL INTERVENTIONS FOR AUTISM:

A SHORT REPORT





Dear Reader,

It has been my pleasure to chair this inquiry by the Westminster Commission on Autism into the issue of harmful interventions for autism. I am so pleased that you have found this short report and I do hope you will join us in spreading awareness on this very important topic.

I am dedicated to doing all I can to make the world a more autism-friendly place and free from charlatans who peddle harmful products, therapies and treatments for autism with no evidence-base.

Healthcare fraud is big business and autism is one of its many targets. Fraudsters promote the use of interventions which can result in physical, social, psychological and financial harm. At worst these interventions could result in death or life-long physical or psychological harm.

Autistic people and their advocates have told us that they have had a range of dangerous and unsubstantiated products and therapies offered or suggested to them. This report makes recommendations for improved policy and practice to ensure that no autistic person is misled into using a product or therapy as an intervention for autism which is unsubstantiated or even harmful.

Most importantly, this report marks the first time that a cross-sector coalition has united with one voice to express its concern and its desire for change on this matter.

It is our hope that this report will set a path for greater attention on this issue and, like the Commission's previous report 'A Spectrum of Obstacles: an Inquiry into Access to Healthcare for Autistic People' will lead to improvements in the lives of autistic people and their families.

I pledge my commitment to doing all I can to ensure that autistic people are free from *any* form of harm; social, physical, psychological or financial and call on you to do the same.

Barry Sheerman MP, Chair of the Westminster Commission on Autism

Commission Members

Parliamentarians:

Barry Sheerman MP (Chair)
Rt Hon. Dame Cheryl Gillan MP
(Chair of the All-Party Parliamentary Group on Autism)
Steve McCabe MP
The Baroness Uddin*
Tim Loughton MP

Autistic Self-Advocates:

Helen Ellis – Autism Public Speaker
Dr Damian Milton* - Researcher, London South Bank University
Craig Kennady* - Trustee, AchieveAbility
Jonathan Andrews – Trustee, Ambitious About Autism
Susan Dunne - Author
Amanda Gibbs - Autism-Awareness Trainer

Charities and Service Providers:

Ambitious About Autism
Autism Alliance UK
Autism Plus
Autism West Midlands
Autistica
Hesley Group
Hidden Impairment National Group
National Autistic Society
National Children's Group
North East Autism Society
Research Autism
The Giving Tree Foundation*

Individuals:

Dame Stephanie Shirley* – Founder of Autistica, Kingwood Trust, Prior's Court School, Autism Cymru and the National Autism Project
Dr Carole Buckley* – Clinical Champion for Autism at the Royal College of General Practitioners
Dr Michael White*- General Practitioner, Hampshire Autism Partnership Board member

Academics:

Professor Emily Simonoff - Professor of Child and Adolescent Psychiatry, King's College London and National Autism Project Strategy Board Member
Dr Liz Pellicano - Director of the Centre for Research in Autism and Education
Professor Nicola Martin* - Head of Research, Law and Social Sciences School LSBU
Richard Mills - Research Director, Research Autism
Professor Simon Baron-Cohen FBA - Director of the Autism Research Centre, Professor of Developmental Psychopathology, University of Cambridge
*Also a parent-advocate.

For a full list of affiliations, please see the Commission's website

Introduction:

Every autistic individual deserves to live a long and happy life; supported to reach their full potential, protected from harm and empowered to enjoy life in the way they want to.

Many autistic people live independent lives while others receive help from family members, schools, carers and support services.

Choosing the right support or the desired interventions can be very difficult for autistic people and their advocates. The Research Autism website lists over 1000 therapies, treatments and interventions for autism. Some suggested interventions are well-researched, well-understood and are recommended by the National Institute for Health and Care Excellence. However, others have no evidence-base or are harmful or illegal yet are still promoted and sold.

It can be difficult to know which interventions are genuine, approved, effective and ethical and which are harmful, unapproved, unethical or a waste of money.

It is critically important that interventions are well-regulated and that assessment of the use of any approach considers the impact on the long-term physical, social and psychological well-being of the person. Interventions and their practitioners or promoters must not be allowed to exploit autistic people for financial or other gain and must be free from conflicts of interest.

The Westminster Commission on Autism has conducted a short inquiry into the regulation of these treatments, therapies and products. This report outlines the rules, regulations and legislation on autism interventions. Then it gives some guidance and advice on choosing interventions. Finally the report makes some recommendations for change.

Gaps in current regulation:

The Westminster Commission on Autism held an evidence session and heard from a number of agencies about how interventions claiming to treat or cure autism are regulated. There are a number of agencies with a role to play in ensuring that harmful interventions for autism are not produced, distributed, sold, used or consumed.

The **Medicines and Healthcare Products Regulatory Agency (MHRA)** has responsibility for the quality, efficacy and safety of medicines.

The **Food Standards Agency** is responsible for food safety. This includes any product for human consumption to be taken orally which is not a 'medicine'.

The **Advertising Standards Authority** seeks to ensure that adverts are responsible and trustworthy.

Trading Standards teams protect consumers from scams, counterfeit products or unfair practices.

The **National Institute for Health and Care Excellence** produce evidence-based guidance and advice for health, public health and social care practitioners

The **Care Quality Commission** is the independent regulator of health and social care in England.

MHRA jurisdiction only covers products which are deemed to be medicines. In order to be a medicine, a product must (1) seek to treat disease and (2) have a physiological action which is consistent with a medicine. The remit of the MHRA is much narrower than the Northern Ireland equivalent, the Health Products Regulatory Authority.

Some harmful interventions, are chemicals which if designed to be taken by mouth, become the responsibility of the Food Standards Agency.

The Commission notes that the name 'Food Standards' is unhelpful since the agency's remit is much broader than what is conventionally considered to be 'food'. This is confusing for individuals looking for advice or to report dangerous products. It is the Commission's view that expanding the remit of the MHRA from regulating medicines to all *health* products would be enormously beneficial.

The Advertising Standards Authority can require evidence including clinical trials from those making claims that an intervention can help an autistic person. If the promoter cannot provide the evidence, they can be asked to remove the claims. However, they would still be permitted to sell the product, they just could not claim that the product can do something for which they do not have the associated evidence. The Commission has been made aware of interventions being sold which do *not* claim to be a treatment for autism but associated claims *are* made in books, social media posts and in face-to-face consultations; all of which are beyond the remit of the Advertising Standards Authority.

The interventions offered to treat or cure autism include social, psychological, medicinal, chemical, dietary and behavioural. As such, some autistic campaigners and others are calling for new legislation, similar to the Cancer Act 1939 to make it illegal to offer to treat, prescribe or promote anything as an intervention (social or biological) for autism unless you are a certified professional.

It is currently far too difficult to determine which agency is responsible for the regulation of the manufacture, promotion, distribution, sale and use of harmful physical, medicinal, psychological or social interventions for autism. Establishing the remit of each agency listed on page 3, identifying potential gaps between them and suggesting possible ways to close the gaps is highly complex. The Commission recommends that the Government urgently convenes the agencies listed alongside others to thoroughly consider the current gaps and look for solutions.

The agencies must produce a publicly available flowchart of their remit and establish a single reporting mechanism for any concern. The Government should reassess the appropriate remit of each organisation and assess the benefits and drawbacks of legislation similar to the Cancer Act 1939.

Our findings

Every aspect of the Commission's work is imbued with the authentic voices of autistic people and their advocates. In conducting this inquiry we heard from over 500 people from the autism community.

Autistic people told us that unsubstantiated and harmful interventions have been offered or suggested to them:

We found that autistic people had been offered treatments such as crystal therapy, ear candles, vitamins, spiritual intervention, aromatherapy, chelation, juice plus diet, hyperbaric oxygen therapy, exorcism, stem-cell transplants, exposure therapy (including slapping), rerum, acupuncture, DAN (defeat autism now) therapy, MMS (bleach), turpentine and many more.

None of the above interventions are evidenced autism interventions, some are dangerous and their use could result in serious harm. The list exposes the vast range of harmful psychological, medicinal, social, dietary and chemical interventions peddled as autism therapies. Currently, there is no single mechanism to report *any* form of intervention that is suspected of causing harm or being unethical. Establishing such a mechanism must be prioritised.

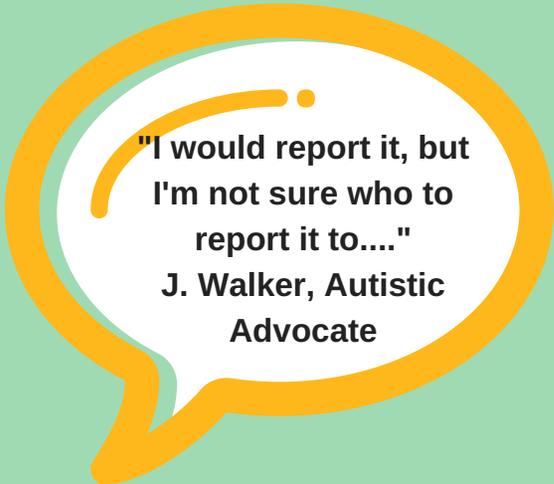
Concerned members of the autistic community told us that they do not know where to report concerns:

Of those who responded to our survey, 44 said they had reported a concern about product or therapy for autism but only 4 of these had reported their concerns to the *appropriate* bodies (trading standards or the advertising standards agency). Zero respondents reported concerns to the MHRA or the Food Standards Agency. The wide range of other bodies to whom concerns were reported demonstrates the poor awareness among the autistic community about where to report concerns. Autistic people and their families told us that they had 'reported' concerns to bodies including the National Autistic Society, the NSPCC, Facebook, local MPs, police and social services.



"There doesn't seem to be a clear mechanism for reporting these things"
Emma Bligh, Autistic and Parent Advocate

89% of those we asked felt that current laws/ regulations for autism treatments/ therapies are **not fit for purpose**



"I would report it, but I'm not sure who to report it to...."
J. Walker, Autistic Advocate

Autism 'cures' in the Media

We do not know the prevalence of this issue. This is partly due to individuals reporting concerns to a vast range of bodies. However, we have found evidence of autistic people being offered unsubstantiated and dangerous interventions. Recent media reports also highlight examples of people selling, promoting and using harmful interventions for autism.

9th May 2016
Lewisham shop 'conning' parents by claiming acupuncture and 'special powder' will cure autism
Jess Clark [@jclarkjourn](#)
reporter

INDY/PULSE

AUTISM: POTENTIALLY LETHAL BLEACH 'CURE' FEARED TO HAVE SPREAD TO BRITAIN



The fake cures for autism that can prove deadly
A campaigner is battling against the dangerous poisons being sold to parents online that claim to treat the condition

13th April 2016
Marlborough man denies selling unregulated drugs to families with autistic children
Patrick McLean
Devizes reporter

News > Health

Chelsea doctor suspended over claims he administered 'dangerous' autism treatment to children

CHLOE CHAPLAIN | 4 days ago

[f](#) [t](#) [e](#)

Click to follow The Evening Standard

EXPOSED: Businessman peddles deadly BLEACH touted as a cure for kids' autism

EXCLUSIVE: 'Miracle Mineral Solution' can cause nausea, diarrhoea, vomiting and ulcers

Parents buying bleach 'cure' for autism

Controversial treatment offered to mum of autistic child by Banstead clinic

By [Surrey Mirror](#) | Posted: November 08, 2016

By Eleanor Davis



STORIES

The therapist/promoter relies on emotional and personal stories to sell their service/product

SCIENTIFIC VIEWS

The therapist/promoter is dismissive of negative scientific findings in relation to their therapy/product



**WARNING
SIGNS OF A
FAKE-THERAPY**

BELIEF & FAITH

The therapy/product is claimed to rely upon belief or faith in order to be successful.



QUALIFICATIONS

The therapy/product can be administered by someone with no training/qualifications



ONE CURE FOR ALL

The product/therapy claims to treat/cure a large range of different conditions



MONEY

The therapy/product is very expensive and the therapist/promoter is making a financial gain



NEW CONDITIONS

The therapist/promoter has diagnosed you with conditions that you did not previously know about and is offering you treatments for them



IF YOU ARE UNSURE...

Always speak to your General Practitioner (GP)



How to report suspicious products or therapies:

To report a problem with a **product** bought in the UK call the Citizens Advice consumer helpline on **03454 04 05 06** (search for Consumerline if you are in Northern Ireland)

For a suspicious **medicine** visit:
fakemeds.campaign.gov.uk

For a product being sold for **human consumption** which is not a medicine email:
foodcrime@foodstandards.gsi.gov.uk

For a **non-medicinal intervention** making claims about autism visit:
www.asa.org.uk/make-a-complaint.html

In addition, if a product is being promoted on **social media**, report it using the platform's
[complaints procedure](#)

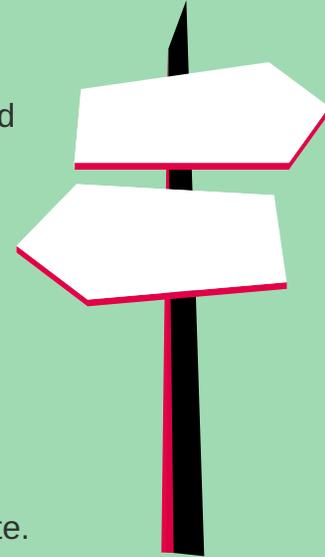
How to choose the right interventions:

Part One

When looking for health or care information, always check that the information meets the NHS Information Standard for health and care information. Look for this logo:



The Information Standard is a certification programme for all organisations producing evidence-based health and care information for the public. Any organisation achieving The Information Standard has undergone a rigorous assessment to check that the information they produce is clear, accurate, balanced, evidence-based and up-to-date.



The commission recommends the following guiding principles*:

1. The intervention is based on a good understanding of autism.
2. The people who deliver the intervention know the person well and respect their feelings and views.
3. The person's capacity for consent is taken into account.
4. The intervention is adapted to the needs of the person receiving it.
5. The intervention is based on a theory that is logical and scientifically feasible.
6. Research evidence shows the intervention can work for people on the autism spectrum.
7. The intervention works in the real world, not just in a research laboratory.
8. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals.
9. The people delivering the intervention follow established guidance.
10. The intervention is carefully monitored and reviewed on a regular basis.
11. The intervention provides significant benefits.
12. The intervention does not cause significant physical or emotional harm.
13. The benefits outweigh any costs (including risks).
14. The intervention is good value for the money and time invested.

*These principles are taken from 'Choosing Autism Interventions: A Research-Based Guide' (2015)

How to choose the right interventions:

Part Two

You can also find useful information on autism interventions via:

The National Autistic Society - <http://www.autism.org.uk/get-involved/media-centre/position-statements/interventions.aspx>

The Autism Alliance - <https://www.autism-alliance.org.uk/about-autism/intervention>

National Institute for Health and Clinical Excellence

<https://www.nice.org.uk/guidance/cg170>

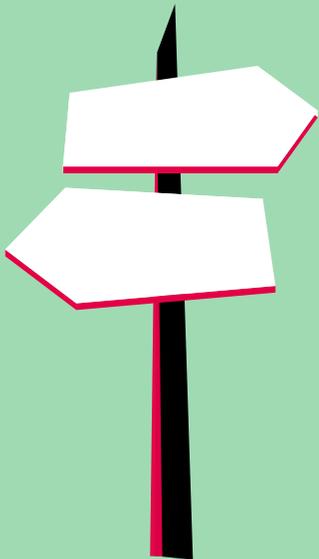
<https://www.nice.org.uk/guidance/cg128>

<https://www.nice.org.uk/guidance/cg142>

Summary of NICE guidelines from Research Autism

http://www.researchautism.net/publicfiles/pdf/nice_guidance_autism_summary.pdf

NHS Choices - <http://www.nhs.uk/Conditions/Autistic-spectrum-disorder/Pages/Treatment.aspx>



Our Recommendations:

- 1 The UK Government should:**

Urgently convene all agencies with regulatory responsibility. Identify the current gaps and reconsider their remits to ensure that all harmful interventions are accounted for. The Commission recommends extending the remit of the MHRA to cover all healthcare products, not just medicines.

Give consideration to the merits and drawbacks of legislative intervention similar to the Cancer Act 1939
- 2 Members of Parliament should:**

Ensure that their caseworkers are trained to proactively escalate concerns from constituents to the relevant authorities
- 3 The Health Select Committee should:**

Consider an inquiry into the promotion and sale of of unsubstantiated products, treatments and therapies
- 4 Charitable organisations should:**

Ensure that their helpline teams are trained to proactively escalate concerns reported to them to the relevant authorities
- 5 Social Media platforms should:**

Update their guidance to ensure that users who promote products/therapies with no evidence base should have their posts removed
- 6 The autism community should:**

Spread awareness of the need to report concerns to the MHRA, FSA, ASA or Trading Standards

The Westminster Commission on Autism is an independent, cross-party, cross-sector coalition of autistic individuals, parent-advocates, Parliamentarians and leaders from the autism 'sector'. The members have a commonality of purpose; to see the world become a more autism-friendly place.

**THE WESTMINSTER
COMMISSION ON
AUTISM**

