



***When "awareness" becomes stigma:
Representations of autism in charity
campaigns and the media, and their
impact on people with autism***

Dr Mitzi Waltz

The Autism Centre, Sheffield Hallam University (UK)



Disability charities and advertising

- Charities can be big businesses, paying high salaries to their executives and spending millions on advertising to ensure a regular flow of donations.
- There is a longstanding problem with how charities portray people with disabilities to gain donations.
- Today, many disability charities are also funded by and (sometimes unwittingly) act as marketing arms for the pharmaceutical industry or other commercial interests.
- A critical approach is crucial now, as in many countries the voluntary sector has increasing responsibility for disability provision and support.



Basics of charity advertising

- Past critiques of charity advertising and stigma looked at the impact of “positive” and “negative” images.
- However, research has shown that disabled and non-disabled people have different views on what a “positive” image is... (Barnett and Hammond, 1999).
- Clear “negative” appeals generate powerful responses based on fear, anger, anxiety, sadness, guilt or pity.
- David Hevey (1992) suggested that most disability charities use **negative appeals**:



“charity advertising sells fear, while commercial advertising sells desire.”



Charity images of autism

- The first known charity images around autism specifically were films made by Bruno Bettelheim for his primary funders from 1956, the Ford Foundation.
- The oldest autism charity, the National Autistic Society (UK), began in 1962, and sought members through newspaper articles and radio interviews rather than adverts. The first of these was “Children In Chains” (1962).



"Children in Chains"

"A newly formed Society for Autistic Children has set to work to awaken the nation to the claims of these sad, lost little souls. It is easy to feel pity for the child physically crippled. Can't we feel pity too for the baby whose mind is locked? And urge, by weight of public opinion, that the nation should provide the keys that will, in the light of today's knowledge, unlock it?"

Reprint from THE EVENING NEWS & STAR, Friday, November 9, 1962

Children in chains

JOHN
Bright - faced and alert of mind but his eyes are still unrel.



DAPHNE is six, with the face of an angel, a sweet smile and a mind of ugliest terror. Once thwarted, she will beat her fair head savagely against the edge of a door, tear her golden hair out by the roots.

NOW SCIENCE KNOWS THAT GOODNESS—EVEN GENIUS—MAY LIE IMPRISONED IN THE DARK MINDS OF THESE MISUNDERSTOOD YOUNGSTERS

by COLIN FRAME



BARBARA
Eyes beauty—but outside her own mind all is hate and terror.

John is a bright-faced eleven, astoundingly good at mental arithmetic although he has never been to school. He can't go—his behaviour is desperately odd. Mad, you would say.

Peter is eight. All day long he dreads an showdown around with him. He can't sleep, plays with the bedclothes and cries down the only friend you would think that he has.

Early diagnosis is obviously vital. The baby child develops quickly. Life is an adventure's growing experience through thousands of children who must have been cured have been written-off in Britain over generations.

But the autistic child locked in his own unreal world, harnessed—however intelligent—

up at home, and when he made a noise in the street I used to cut up and die.

Now when, perhaps he plunges his hands excitedly into the box of tissues and kisses up a fuss about choosing one. I am getting hard.

For this illness can strike at any age, even in the womb. Other symptoms are that the child can do some things well, even brilliantly, and be totally backward in others. And that his speech is abnormal.

Some autistic children have been treated as deaf mutes. They do not answer. They just do not listen.

They are prisoners of their mind and the outer world has no meaning and cannot penetrate. Sometimes they talk clearly, sometimes utter gibberish.

They do not understand who they are, who their brothers and sisters are, who the visitor is.

They discovered 200 of them in 1959; how many there are there in London? Those who say 2,000 may now be far out.

Mr. Compton Carr, MP for Haverhill, who is making a special study of this subject, told me: "In Denmark recently I saw formerly autistic children sitting side by side with normal children at school and doing well."

What riddles most with these parents is the feeling that something can and should be done for these unhappy children before it is too late and as a doctor put it to me: "go downhill into idiocy."

It is not many parents who in the past now today a few mind specialists, doctors and hospitals know it to be true.

At Henley, for instance, there is a hospital where autistic children are slowly being made socially and even educationally acceptable. Some have gone on to ordinary school and done well.

One fascinating experiment there was to use sub-normal girls being trained for domestic jobs—minders and "beautified" mothers—told these children, awakening them to some form of emotional relationship at last.

But further treatment, to give the same individual attention, demands a large and specialised staff.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

THE NEED

Massive is a development Society for Autistic Children has set to work to awaken the nation to the claims of these sad, lost little souls.

More knowledge, more understanding, more expert treatment, more schools—these are the aims of the society whose secretary, Mrs. Helen Green Allison, lives at 100, Wiseman, Mill Hill, London.

It is a pitiful thought that, through lack of knowledge which is only now beginning to seep through, thousands of children who must have been cured have been written-off in Britain over generations.

BIG SUCCESS

In Toronto, a special day nursery has had startling success with autistic infants, leading them gently along to normal knowledge, unlock it?



“Children in Chains”

- This article cemented some of the most enduring mental images of autism: that the disability was puzzling, that a “normal” child was somewhere inside the autistic shell, and that the focus should be on “rescuing” this “normal” child. Autistic adults were invisible.
- Like Bettelheim’s films for the Ford Foundation, and like adverts from similar organisations then and now, it also established others (professionals and/or parents) as those who should speak on behalf of people with autism.
- The stigma attached here is one that removes agency from the labeled person, and that applies fearful adjectives to behaviours that differ from the norm.
- It attempts to remove stigma from parents, by positioning autism as a mental illness that can be cured.



Autism advertising, 1950s-1980s

- However, autism charities generally did not advertise during the “Bettelheim era”—to be a member of such a group was still tantamount to an admission of child abuse/neglect. Autism charity funds were raised through sales (NAS Christmas cards, etc.) and from payment for schools and services.
- Some newspaper and magazine stories were used to raise funds for therapeutic programmes, however.
- The article at right described children “whose uncontrolled madness had turned their homes into hells”—a stigma that was used to justify hitting, shocking and restraining them at Ivar Lovaas’s UCLA lab.
- Stigma can, as in this example, literally dehumanise people, providing an excuse for abuse.

A surprising, shocking treatment
helps far-gone mental cripples

Photographed
by ALLAN GRANT

Screams, Slaps and Love



Enraged bellows at the boy, then a sharp slap in the face. This deliberate, calculated harshness is part of an extraordinary new treatment for mentally crippled children. It is based on the old-fashioned idea that the way to bring up children is to reward them when they're good, punish them when they're bad. At the University of California in Los Angeles, a team of researchers is applying this precept to extreme cases. They have taken on three boys and a girl with a special form of schizophrenia called autism—utterly withdrawn children whose minds are sealed against all human contact and whose uncontrolled madness had turned their homes into hells (p. 96). And, by alternating methods of shocking roughness with persistent and loving attention, the researchers have broken through the first barriers.





The era of “awareness”

- Most of you will be too young to remember AIDS before AZT... when most people still thought you could catch it from toilet seats, and blamed the victims.
- AIDS awareness campaigns emerged in the late 1980s as an attempt to educate the public and dispel the stigma attached to the illness; subsequent awareness campaigns (such as those for celiac disease and breast cancer) have had similar noble aims.
- However, there is another side to awareness: as Ben Goldacre (2012) and others have documented, “awareness” campaigns and links with advocacy groups have now become a key part of pharmaceutical firms’ marketing plans. When you hear news stories about growing prevalence or patients/families demanding access to medications/ treatments, or when lawmakers are flooded with appeals, this can be part of a marketing campaign.



The era of “awareness”

- For industry the purpose of the awareness campaign is to encourage the public to see something as a disease state, and to seek treatment for it.
- Goldacre quotes a health-care public relations specialist explaining how this works to the readers of *Pharmaceutical Executive*:

“Years before a new drug is launched, pharma companies and advocacy teams should map out how strong ties can advance corporate goals and brand objectives. Product managers see advocacy groups as allies to help advance brand objectives, like increasing disease awareness, building demand for new treatments, and helping facilitate FDA clearance of their drug.”

-- Durand, M (2006), cited in Goldacre (2012), pp. 267-268



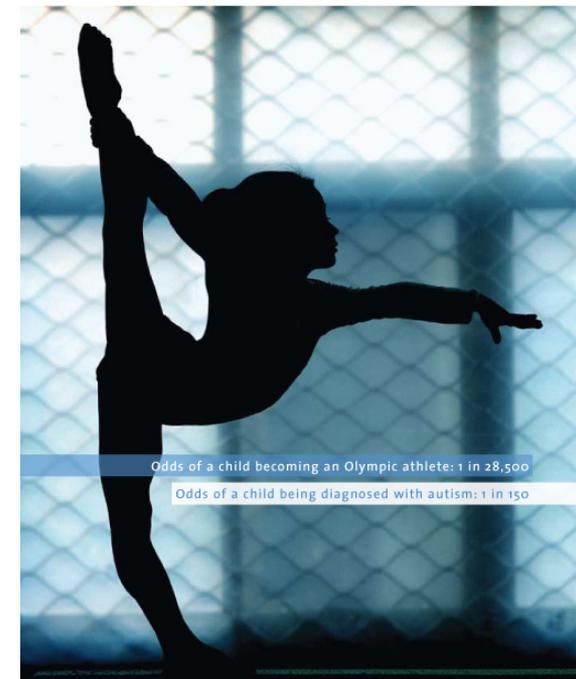
Which is why you shouldn't be surprised...

- That in 2011, Robert Ring, PhD, who had two years earlier led the world's first autism-specific drug development group (Pfizer's Autism Spectrum Disorders Unit), became the vice president for translational research for the world's largest autism charity, Autism Speaks. ("Translational research" usually means turning insights from research into marketable medicines or devices).
- That Autism Speaks' executive vice president, Peter Bell, joined the group following his success *as a marketing executive* in getting Risperdal (risperidone) approved by the FDA as a treatment for "agitation" in people with autism for his previous employer, McNeil Pharmaceuticals, and arm of the pharmaceutical conglomerate Johnson & Johnson (based on *very little* research, none of which considered long-term impact on neurodevelopment...)

...but you might want to be concerned

“Autism awareness” campaigns

- “Autism awareness” is the core of most current autism advertising campaigns. But what do they make us “aware” of?
- Basic brand awareness is the first goal for advertising any product.
- It also fits into the first stage of Hevey’s formula for typical charity advertising, in which adverts set up a negative image (the **problem**) and place the named charity as the **solution**. What do you learn about autism from these two “awareness” adverts?





What does “awareness” do?

- Charities whose main mission is “awareness” need do no more than publish some information, such as the number of people affected by autism.
- For example, the US-based Autism Spectrum Disorders Foundation spent less than .3% of its income on families affected by autism—the rest went for fundraising costs (Seidel, 2009).
- This is clearly a form of fraud—but what most other charities market is... themselves.



Every 20 minutes a child is diagnosed with autism.

To learn more about autism visit
www.myasdf.org/wingsofhope.



Please start your Wings of Hope kit today.
If you have any letters left over, feel free to
hand them out to your family and friends.
Autism Spectrum Disorder Foundation

More children will be diagnosed with autism this year
than with AIDS, diabetes and cancer combined.

To learn more about autism visit
www.myasdf.org/wingsofhope.

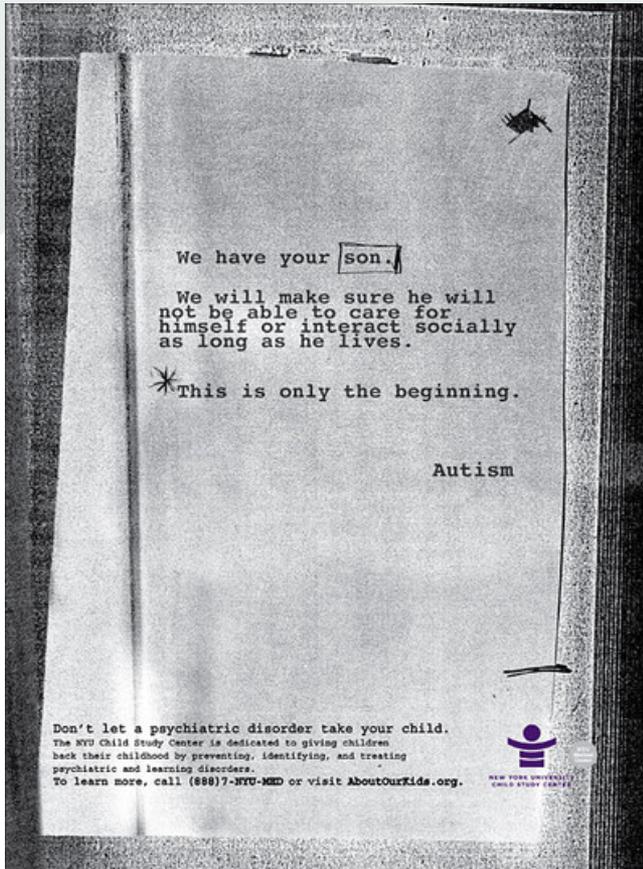
Autism Spectrum Disorder Foundation

“Autism monster” campaigns

- Some go to great lengths to demonise children with autism as a way to build greater sympathy, bigger donations (and potentially more pressure for “treatment”).)
- Action for Children ran a UK campaign that showed autism as a “monster” within which a normal child was trapped—unless he could attend its school.
- Autism Speaks, released a film whose script included:
“I am autism...I know where you live...I work faster than pediatric AIDS, cancer and diabetes combined. And if you’re happily married, I will make sure that your marriage fails. Your money will fall into my hands and I will bankrupt you for my own self-gain...I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain...I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness.”



Positioning child as victim, autism as terrorist or kidnapper

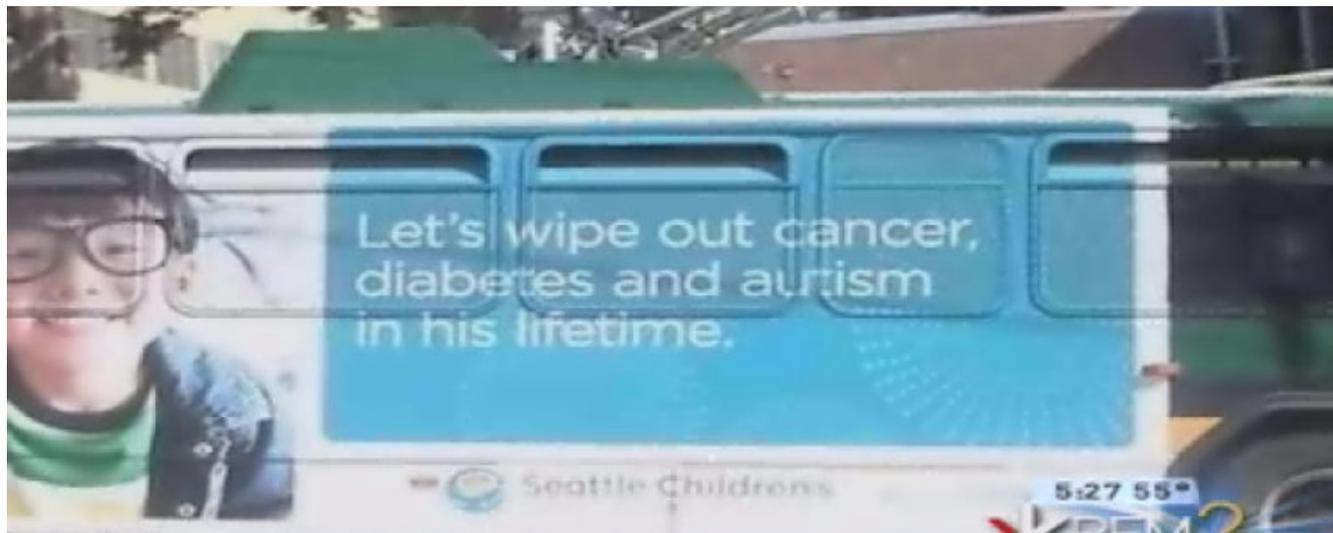


- New York University Child Study Centre's "Ransom Notes" campaign is a highly controversial example, equating children with autism to victims of terrorism or kidnapping.
- This particular representation is part of a longstanding pattern, going right back to earlier notions of a "normal" child who needs to be rescued by science.



The impact of medicalisation

- In keeping with the strategy described earlier, what many of the largest autism charities are now selling is **the idea of autism as a medical condition**—devastating but potentially curable. This is often done by equating it with other medical conditions.
- This attaches huge stigma to those affected: stigma that can attract pity, “heroic treatment,” and lack of understanding when the expected cure does not materialise.





Follow the money...

- Why the rush towards more medicalisation? (see answer above)
- There are currently at least 10 drugs in pre-clinical (Phase 1) development, 10 in Phase II, and 6 in Phase III for autism. The majority of these are existing medications, which if licensed for a new use can be re-patented, or “me-too” copies of existing drugs. Several of them are drugs that with known, serious side-effect profiles.
- There is no such thing as a drug that can treat a developmental difference—these drugs are used to control behaviour, which means we fail to look at the impact of people, environments and demands on behaviour.
- Of course, in the world of autism, it’s not just drug companies with commercial interests: private school chains, care home companies, and medicalised therapies also lobby and fund charities.



An insider's tale...

- And the impact goes deeper than you might think. I've had recent experience of the impact of these funding relationships myself...
- A (non-autism) charity was awarded a contract by the US Centres for Disease Control, a public body, to create a patient Web site for people with the condition they support.
- I was asked to supply some evidence-based content for the Web site: advice about common health issues with a condition-specific "spin," written in patient-friendly language.
- The content, which included some standard cautions about medication side effects, was vetted by the charity's "medical board"—made up entirely of people who are partially or fully funded by the pharmaceutical industry.
- It will not be running unless these standard, evidence-based cautions are removed...



Talking back to autism charities

- One of the most interesting developments in the past few years has been people with autism using the Internet to respond directly to charity advertising that demonises them.





Can involvement of people with autism change charity advertising?

- The “Don’t Write Me Off” campaign from the NAS is a notable example of how campaign goals can change when charities are guided by disabled people.
- It includes many suggestions for practical and policy changes in the benefits system.





Can involvement of people with autism change charity advertising?

- In the Netherlands, AutismeTopTen (www.autismetentop.nl) is another initiative that has had strong involvement from people with autism, resulting in a positive campaign focused on autistic strengths that can benefit employees and employers.

Beeldvormingscampagne Autisme & werk
AutismeTenTop
Investeren in het talent van mensen met (een
vorm van) autisme loont!

Nauwelijks benut arbeidspotentieel

Over deze campagne

Mensen met een vorm van autisme (ASS) vormen een uniek en nauwelijks benut arbeidspotentieel dat véél voor werkgevers kan betekenen. Door middel van de beeldvormingscampagne Autisme Ten Top willen wij als [initiatiefnemers](#), werkgevers laten kennismaken met deze groep potentiële werknemers, stigma's rondom autisme doorbreken en tegelijkertijd laten zien hoe zij mensen met een vorm van autisme optimaal kunnen inzetten binnen hun bedrijfsproces. Werkgevers kunnen zo ook ontdekken hoe dit perfect aansluit op hun MVO- en diversiteitsbeleid en hoe zij hiermee de personeelstekorten van de toekomst voor kunnen zijn.

Mensen met een vorm van autisme zijn stuk voor stuk individuen, elk met zijn of haar eigen kracht, talenten en zaken waar ze minder sterk in zijn. Eventueel benodigde aanpassingen aan de werkplek en omgeving worden dus vooral door het karakter en de eigenschappen van het individu bepaald. Vaak gaat het hierbij om niet meer dan enkele eenvoudige aanpassingen, zoals een prikkelarme omgeving, duidelijke afspraken en een vast aanspreekpunt, om een optimale werkplek te creëren.

Er zijn binnen de groep mensen met autisme natuurlijk ook mensen die zonder dergelijke aanpassingen goed kunnen functioneren. Toch kan het voor hen ook belangrijk zijn als de werkgever van hun vorm van autisme op de hoogte is en zodoende flexibel kan reageren op het moment dat het autisme zich openbaart.



Over deze campagne

Mensen met een vorm van autisme (ASS) vormen een uniek en nauwelijks benut arbeidspotentieel dat véél voor werkgevers kan betekenen. Door middel van de beeldvormingscampagne

Autisme Ten Top willen wij als [initiatiefneme...](#)
[meer](#)

Menu

Over deze campagne

[6 Pijlers](#)

[Initiatiefnemers](#)

[LinkedIn groep](#)

[Succesverhalen](#)

[Bijeenkomsten](#)

[Contact](#)

[Downloads & Links](#)

[Vraag & Aanbod](#)

[Nieuws & artikelen](#)

It could be better, and that is up to us

- Many good and well-intentioned people work for or donate to charities.
- Many charities do at least some fantastic work.
- However, most disability-related charities don't see putting themselves out of business as a goal: to survive (and people's well-paid jobs depend on their survival) they must continue to create a "need" for their services.
- As noted, they can also be used by other entities as a marketing tool.
- These factors mean that we need to question whether the attachment of stigma to people with disabilities by charities is accidental or intentional, challenge it when it happens, and question the positioning of disabled people as in need of charity rather than acceptance, accommodation, equal rights and justice.

NOTE: I have analysed charity representations in detail, including interviewing creatives about how campaigns are developed, in an article:

Waltz, M. (2012) "Images and narratives of autism within charity discourses," *Disability & Society*, 27 (2): pp. 219-233.



References

- Barnett, J. and Hammond, S. (1999) “Representing disability in charity promotions,” *Journal of Community and Applied Social Psychology*, 9 (4): 309-314.
- Fleischer, D. and Zames, F. (2001) *The Disability Rights Movement: From Charity to Confrontation*. Philadelphia: Temple University Press.
- Goldacre, B. (2012) *Bad Pharma*. London: Fourth Estate.
- Hevey, D. (1992) *The Creatures Time Forgot: Photography and Disability Imagery*. London: Routledge.
- Hevey, D. (1992 b) “Fear for Sale,” *New Internationalist*, 233.

References

- Redmond, S. Downie, M., Rennison, R. and Batten, A. (2009) “Don’t Write Me Off: Make the System Fair for People with Autism.” London: National Autistic Society.
- Rosenblatt, M. (2009) “I Exist: The Message From Adults With Autism in England.” London: National Autistic Society.
- Seidel, K. (2009) “Waist Deep in the Autism Fundraising Hole.” Online at: <http://www.neurodiversity.com/weblog/article/197> [Accessed 2 January 2010]



*Sheffield
Hallam University*

Faculty of
Development
and Society

Contact details:

Dr Mitzi Waltz

+31 (0)630053134

mitziwaltz@yahoo.com

www.mitziwaltz.com

UNIVERSITY OF
BIRMINGHAM