



Participation, Inclusion & Exclusion in the 21st Century

Is Inclusion a Myth?

Special Report

“Hard to reach” - We Think Not!

Communications Disorders & Our Exclusion in the 21st Century

Written by
Joshua Harris, Dr Carole Harris, & Wendy Stern

Effect of communications disorders on our daily lives &:

- Corporate enforcement, regulation, compliance and value for money
- Public Sector effectiveness: accountability, governance, transparency
- The extent that local authorities empower people to take control

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Dedication and acknowledgements to our late Chairman, Paul Lowen

We are dedicating this, our first report, to our late Chairman, Paul Lowen, who passed away on 25th March 2006, having been critically ill for a considerable while since 1999.

With great vision, Paul, also a member of the Power Inquiry's Sheffield Event Team anticipated that the Power Inquiry would continue to encourage political involvement and participation.

As our guiding light, Paul played a significant part in developing strategy and thinking both for our Power Inquiry Sheffield Event and as the founder of Action for Involvement.

We were most fortunate to enjoy the benefit of his survey design expertise to develop our questionnaire with co-author of 18 years, Wendy Stern. Together, they were instrumental in producing our Power Inquiry Sheffield Event Report in September 2005 and set the standard for future publications.

Paul will be very sadly missed by us all with condolences to his family; his obituary, published in the Guardian on 1st March 2007 is at www.guardian.co.uk/otherlives/story/0,,2023672,00.html.



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ABOUT US

Inspired by Paul Lowen our late Chairman, Action for Involvement evolved out of our Power Inquiry investigations in to political involvement, inclusion and participation. Chaired by Baroness Helena Kennedy QC, the Power Inquiry is funded by the Joseph Rowntree Charitable Trust.

On completing our work for the Power Inquiry, we re-grouped in 2006. We then made a successful bid to the Big Lottery Fund's Awards scheme for All in order to organise and deliver events, similar to one we had delivered for the Power Inquiry in September 2005 at Sheffield Hallam University.

Action for involvement is a community-based consumer action group concerned with ensuring people benefit from the introduction of corporate governance and social responsibility in to the Public and Private Sectors.

As such we aim to create greater awareness of:

- Corporate enforcement, regulation, compliance and value for money
- Public Sector effectiveness: accountability, governance, transparency
- The extent that local authorities empower people to take control

Our aim and core mission is to educate people in our communities alongside public and private sector of the need for a fair exchange of corporate governance and corporate social responsibility affects Public/Private Sector relationships in order to bring about better service delivery and improve the quality of our lives.

We are fortunate to have a dynamic, enthused and strong team with a wide range of expertise who relate to, and understand, the issues of disaffection affecting our community.



PART I: REPORT FRAMEWORK

TERMS OF REFERENCE

Special Report authors, Joshua (Josh) Harris, Carole Harris and Wendy Stern explore access and accessibility with particular reference to people with disabling communications disorders and how to meet related needs for involvement and participation.

FOCUS

Issues and concepts central to invisible disabilities, access and accessibility with particular reference to communications disorders will focus upon:

- those who control the lives we live and
- whether we care who these people are who control our lives?

PURPOSE

Create a viable means for people with communications disorders to explore issues affecting political involvement, participation and inclusion to feed in to our investigations and report findings to decision makers.

We have taken great pains to ensure our report represents concerns resulting out of our experiences from disabling communications disorders.

- Part I: Special Report Framework
- Part II: Executive Summary
- Part III: Introducing our World - The Reality
- Part IV: Conclusion - Our Inherited Challenge

METHODS USED

We developed this Special Report out of issues which our Event Speakers, Ashley Sweetland and Magda Read raised on “hard to reach” groups at our November 2006 Event. This report is to be taken on an “as is” basis. Other conclusions or inferences may not be drawn from the synopsis or reports. We make extensive use of personal anecdote as a means to report our concerns regarding the way people in organisations and our social networks conduct matters on our behalf. We communicated via email and relied on Dr Carole Harris to assist us in clarifying the many issues affecting us. In attempting to find practical, cost-effective solutions we evaluated public, private and not-for-profit sector practices with Internet and related technologies as a way forward.

PART II: EXECUTIVE SUMMARY

As a community-based organisation concerned with involvement and inclusion our Special Report reflects concerns raised by Josh Harris and Wendy Stern who have communications disorders restricting their involvement. They are as concerned by the apparent inability to manage vital debates.

Our Special Report explores the day-to-day practicalities affecting the little understood realm of such disorders particularly regarding education, healthcare, information processing and communicating with the world around us.

That disabled people are deemed “*hard to reach*” some 12 years after enabling legislation was introduced is unacceptable. It suggests that mainstream society does not recognise and therefore sees no need to ensure suitable facilities exist to communicate with people who have communications disorders.

Phraseology such as “*hard to reach*” is used with the danger of failing to recognise that within the collective term many distinct groups exist, each with their own specific and differing needs.

On this, Josh writes about being profoundly autistic and included as follows:

“People have to listen to our voices in the wilderness of disability We know what we need if you can find a way to hear us. You talk about inclusion but I say it goes much deeper. You need to see our equal alongside everyone else. I believe we really need to teach that autism is the enemy not *us* personally. To have our selfhood accepted and not our disability is the most important thing. Some people feel that having a disability kills every thought in your head and with it your place in the community.” (Jewish Tribune, 26th February 2007)

Practical issues include the need to be far more focussed on achieving quality results to draw in and involve such people. Of particular concern to us is the:

- tick box mentality to access, accessibility and invisible disabilities,
- handling our personal data,
- lack of adequate expenditure on suitable facilities
- poor use of information technology
- compelling need to find long-term solutions rather than a quick fix.

In attempting to find practical, cost-effective solutions we evaluated public, private and not-for-profit sector practices with Internet and related technologies as a way forward.



We reiterate concerns regarding the failure of decision-makers to involve or inform us as to the why's and wherefore's of decisions before enactment. This includes the undesirable practice of conducting case conferences behind the scenes without our knowledge and involvement.

Serious concerns exist vis-à-vis reaching out to supposedly “hard to reach” groups; we think setting targets is all very well but it must be subject to the emphasis on quantity *and* quality of engagement. Difficulties may well be due to an apparent inability of service providers to offer accessible, transparent and accountable facilities.

Greater transparency and accountability is therefore vital to ensure systems governing us are seen to be fairer, more just and equitable.

We must think far more creatively and laterally to find ways of reaching out to, and involving people like us to achieve our involvement and participation.

PART III: INTRODUCING OUR WORLD - THE REALITY

Concepts such as “hard to reach” is unhelpful for us because it implies that our difficulties are the same as many other, well-addressed issues affecting the young, deaf, blind and elderly. We fear that the use of such general phrases is quite likely to indicate a lack of understanding of the real issues in question.

Disability, Invisible Disability & Accessibility

Little is understood of communications disorders or the ensuing deep sense of isolation and setbacks. It is a rare opportunity to give a personal account of experiences as a result of an apparent lack of resources to offer reasonable support for voice loss sufferers like myself and the way we as a group may be treated by the general public and organisations alike.

Voice is the vital identifier for gender, age, emotional state, nationality and other origins. It is the first impression we give and receive when we can not be seen, for example, speaking on the phone.

Until Wendy lost her voice in 2004, she had not realised the extent to which voice is closely tied to identity or its effect on the relationships we have with ourselves and others.

After a lifetime with a normal voice, Wendy was therefore ill-equipped to manage the transition and ensuing stress in a world which now encompassed a disabling speech impairment. She was as ill-prepared for the inappropriate advice and interventions which she found to be of limited use and without any prospect of improvement; it has since reinforced her views and experiences regarding organisational inaccessibility.

With no voice, what remained could be compared to a cartoon voice over. As Josh writes “people without a voice are irrevocably isolated” and that is how she felt “stripped of my identity, excluded and deep sense of isolation”.

Access, Accessibility and Disability Discrimination

This begs the issue of what does access and accessibility *mean* in practical terms to people suffering from lesser known communications disabilities.

Crucially, however, we must first understand that *accessibility* is not only to give accessibility in buildings for wheelchair users, or to be fitted with audio loops for deaf people or that road crossings are fitted with tactile bumps for blind people.

Accessibility is as much about enabling those with invisible conditions such as lupus, cancer, Parkinson's, motor & chronic pain disorders, heart disease, autism and speech impairments to access and enjoy the use of services and facilities.

And just why does this lack of accessibility still exist after nearly 10 years of increasing disability awareness under the Disability Discrimination Act 1995?

As importantly what does accessibility mean to those, who like Josh and Wendy, have disabling communications disorders; or, our late Chairman, Paul, who suffered with chronic pain after breaking his back in 1999.

Accessibility requires organisations to respect the needs of our disability and ensuring that suitable arrangements are made to include wide-ranging disabilities at meetings, for example.

For people with communications disorders like Josh and Wendy, arrangements have to be made for them to communicate effectively. By this we mean sending prompt, fully informed replies to faxes, emails or text messages and allowing more time for our replies. It may also mean supplying a keyboard with monitor so that we can communicate what we need to say with ease, whether this is for buying rail tickets or discussing other more complex matters.

Exaggerated, deliberately slow and pronounced manner when speaking to us is also unacceptable, the inference being our speech disorders affects our ability to hear and understand what people say to us and the people around us.

That organisations are inappropriately set up for us leads to lack of transparency and mis-labelling as "*hard to reach*". For Wendy, recent, extremely variable and total voice loss is devastating, while for Josh his communications and behavioural impairments is devastating in other ways. That we do our utmost to reach out to others suggests mis-labelling - a fact of life for people like Josh and Wendy.

Education for Inclusion

Of special schools, Josh says that "terrible boredom grabs hold of you and you forget the person that you are". Incidents happened where teaching staff treated Josh as vacuous with professionals casting aspersions on his behaviour and communications difficulties. Therefore, until Josh learned to type and was able to release his communications skills

"everyone thought [Josh] was stupid because "killer autism" really had [him] in its terrifying power. It is ridiculous when experts say, "most autistic people do not understand what other people are saying and cannot comprehend why people talk to one another." It is false; easy for the experts to say. Have they been stuck in a body that won't do as you desire thinking the thoughts of a genius? I think not!"

Personal assistants, friends and family may make choices about decisions without consulting or including Josh by adopting a custodial caring role. Those who love Josh contend with the need to avoid patronising his behaviour.

This reflects Wendy's experience in seeking to secure her inclusion. She feels that Public and Private Sector organisations disregard her to the extent that it results in poor service or practice. Her inputs and related reports are altered to suit an agenda unrelated to her concerns of disability and accessibility.

One hopes such service is only confined to those with disabilities. Although disabled people may not be singled out, these practices may be far more wide-ranging. Organisations seem far heavier-handed in their dealings with disabled people. We suspect such practices impact on local and community involvement with many people less involved than they may wish.

It may therefore be questionable whether we are educated for inclusion or whether such education is intended to reinforce the psychological barriers in order to maintain the status quo.

Psychological Morality of Inclusion & Accessibility

That speech impaired people like Josh and Wendy do not have their needs met, can - we think - be due to the intolerance of inherently lazy people with fixed mind-sets. People as a group have a natural tendency to reject those who do not conform to their "norm".

A person with any difference will find the greatest barrier is not what makes them different but the attitudes of others in relationship to themselves, be this a professional of long-standing or an inexperienced locum keen to forge a career.

The difficulty does not create the barrier that makes people hard to reach; it is people's attitudes and actions which combine to obstruct scope for meaningful involvement. "Hard to reach" is therefore an incorrect classification which causes prejudice and artificially disadvantages disabled people potentially causing us to express ourselves inappropriately.

All members of any organisation have moral and social obligations reinforced by legal requirements to ensure no-one is treated badly regardless of condition. As such, no legal justification exists to exclude, dissuade, or otherwise discourage individuals from making a meaningful contribution to any consultation affecting their life. By this, Wendy means the practice of case conferences by legal, medical, financial services and other professionals without the affected parties.

The greater the challenge an individual contends with, the greater the barrier they face and exposure to liability of the salient organisation's potential irregularities.

Like Wendy, Josh “wants people to be more helpful to create accessibility and is concerned ... they reject others just so everybody feels better about themselves. Peoples’ attitudes are easily the weeds reaching to really strangle. Typing is a way to access resources and with goodwill on both sides can facilitate better communications.” (J. Harris, Facilitated Communications, 2004, 2006)

Inclusion, Advocacy & Self-Advocacy

Achieving equality for people with communications disorders entails far greater self-awareness because if we do not know our needs and what they are, who does and how can they communicate them to others in a manner acceptable to us?

Much is spoken of the power of advocacy and self-advocacy in achieving inclusion; it also seems to be the way forward for people with communication difficulties such as those affecting people like Josh and Wendy.

Advocacy and self-advocacy as a means of inclusion takes great courage for us. We require strong support to be viable and achieve our potential. Crucially, people around us need to recognise and appreciate that we are *not* just the sum total of our disabilities.

We place our trust in others to achieve our aims, objectives and aspirations. It is a constant battle to protect our boundaries of respect *and* self-respect; to ensure they are maintained, not eroded by those who see our dependence as equating to our being lesser, regardless of our clarity of expression. For us to be included, our assistants, support workers, professional advisors, colleagues, family and friends therefore need to ensure they include us in consultations and decisions.

We also need the organisations that we have to deal with to co-operate with us and our agents to ensure we live in a meaningful way. We are therefore entitled to expect full control over our personal data, when and to whom such material is disclosed *and*, as importantly, how it is used. Questions arise as regards the extent to which support workers and organisations may “cut corners” to liaise without reference to us, the client.

It is as important to bear in mind that our communication difficulties, inhibit the smooth flow of everyday life. Inevitably even making travel bookings can take at least 20 minutes, even using communication boards or text to speech software.

By far the hardest aspect of all this is to challenge the “perceived wisdom” of existing professionals whether educationalists, medical specialists or the like. As Josh says “organisations do not meet the needs of individuals who have specific and complex needs [which] need to think more genuinely because they refuse to make acceptable changes to the criteria used.” (J. Harris, Facilitated Communications, 2004, 2006)

Implementing our Inclusion??

In the words of Bob Dylan "you don't need to be a weatherman to know which way the wind blows" (*Homesick Blues, 1965*).

Wendy says she "felt like a stranger in a strange land" on finding organisations, including government offices, would not extend submission deadlines and replies did not then relate to queries; her expectations were founded on the belief that our systems and procedures are fair and flexible in such situations.

Her struggles as a voice impaired professional receiving persistent unsympathetic treatment by public and private staff alike inexcusably includes:

- her landlord, a Social Housing Association has failed to make any reasonable adjustments in any aspect of its service delivery to accommodate her disability
- the same landlord on learning she was the executor for a deceased tenant failed to deal with her in an appropriately civil and dignified manner
- Consultants of a specialist unit responsible for terminal medical conditions displaying similar intolerance.
- Ironically Wendy sits on various Council bodies to consider the access and accessibility of local services yet staff refused to spend the small sum to pay for speech software that would enable her to contribute at meetings.
- It is particularly unsettling that Labour Party MP's fail to reply to emails, faxes and Recorded Delivery letters regarding these issues
- Preparations for all legal process including Ombudsman services take longer to prepare than the norm, yet no allowance is made for the needs of this disability

Not even the Royal Courts of Justice are exempt from such practices - they too failed to make the necessary adaptations to enable a voice impaired claimant to communicate effectively over a non-executable, unenforceable finance agreement for a defective IT system. The claimant could not be heard or understood and directions as to how to compensate for this were not applied as directed.

Although Courts purported to accommodate this disability, this speech impairment made it difficult to instruct others to act for her particularly in Court, where the hearings are not geared up to handling disabilities of this nature. It is hard to say whether representation would have assisted. This difficulty in instructing others to act makes pursuit of day-to-day and legal entitlements an inaccessible dream.



BBC Radio 4's Law in Action, (12th June 2006) investigates whether the Mental Capacity Act is serving its purpose. It is designed to help patients who lack the capacity to make their own decisions and can not consent to their treatment. They report that:

Thousands of people are kept in hospital without being formally sectioned under the Mental Health Act and without the safeguards that legislation affords. This is known as the 'Bournemouth Gap' after a legal case involving a hospital authority which kept an autistic man in hospital. This decision was challenged by his carers all the way to the European Court. Leading mental health lawyers, Lucy Scott Montcrieff and Nicola Macintosh, [report] their concerns that “the Mental Capacity Act does not give vulnerable adults the same protections as those for people detained under the Mental Health Act” and that this applies in a similar way to care of the elderly, particularly those people with dementia.

If the legislation designed to protect us from harm is proving ineffective it must be the case that the regulatory systems designed to achieve these objectives are not working. Where can we turn to be heard and, if necessary, have our legal rights enforced?

PART III: CONCLUSION - OUR UNRELENTING CHALLENGE

Concepts such as “hard to reach” is unhelpful because it is a form of mis-labelling which implies our difficulties are the same as many other, well-addressed issues affecting the young, deaf, blind and elderly. We fear that the use of such general phrases could indicate a lack of understanding of the real issues in question.

Technology exists and we can use it to facilitate our inclusion. For communications disorders such as ours, facilitated typing and typing are effective in ensuring greater clarity when we communicate with others.

Although still a long way to go, technology reinforced by strong advocacy, self-advocacy, determination and assertiveness is integral to ensure and secure our respect, successful involvement and inclusion.

Likewise while we may well have a plethora of resources, the Bodies which exist as a backstop, need to find more constructive ways to support us in playing our part.

So much more can be achieved by finding effective ways to draw on our talent, build up our potential and include us in our communities.



Appendix A

ABOUT OUR AUTHORS

Joshua Harris

At 18, Josh has overcome the debilitating disability of autism to secure a place in mainstream education and will be attending a College of Advanced Jewish Studies and University next academic year. Josh has written a DVD "Joshua's World" to describe sensory aberrations he experiences and compensatory behaviours he has to adopt just to function. Social workers, psychologists and educationalists in Salford, Russia, America and Australia use the DVD Josh developed as a teaching aid. Josh, who wrote all of the content for his soon to be launched website about autism, will also use it to publish his DVD. A DVD on other aspects of autism is pending. With his Personal Assistants' support, Josh adapted his communications board into other languages also to be publicised on his website. Josh has published articles in professional journals and other publications about autism and inclusion.

Dr Carole Harris, NB, BF, DCh, D.R.C.O.G.

Carole Harris qualified in 1975 as a Doctor of Medicine at Guys Hospital, London and worked in various teaching hospitals before moving to Manchester to become a Principal in General Practice. Following diagnosis of Autism in Joshua, the first of her 3 children, Carole lessened work commitments to research the diagnosis and help better his life. Her inspired quest resulted in many challenges covering a range of technical and specialist areas encompassing sensory integration, communication difficulties, language therapies, Medicine - both conventional and alternative and Education both special and inclusive.

Wendy Stern

Secretary and co-founder of Action for Involvement, Wendy delivered a Sheffield Event for the Power Inquiry funded by the Joseph Rowntree Charitable Trust and chaired by Baroness Helena Kennedy QC. An alumni of Sheffield Business School, Wendy read her M.Sc. in Organisation Development in 1986 going part-time to help care for terminally-ill relatives. Wendy's career took her to Europe, Middle East and States. International management development and research projects includes British Steel, The Industrial Society, Sheppard Moscow Organisational Development Consultancy, Nat West Bank's Corporate Banking arm, British Psychological Society, British & East European Psychology Group and H.M. Gov't.s Insolvency Services often co-authored with her late colleague, Paul Lowen. Until 2006, Wendy was a Trustee of a specialist Housing Association and sits on her Council's Access Liaison Group. A support services provider recently appointed her to their Board's Operations Committee. Since becoming speech impaired following an urgent medical procedure in 2004, Wendy has worked hard to overcome obstacles posed to her professional life.





Appendix B

ACKNOWLEDGEMENTS

We are most grateful to everyone who supported us in producing a separate Special Report on communications needs and its affect on people with disabling speech impairments in their ability to contribute to wider society.

We wish to make particular mention of the time and support from Dr Carole Harris, Trevor Simon, Martin Brighton, Dr Lorna Warren, Mohamad Gamal, Pete Bradfield, Ashley Sweetland, Magda Read and Joe Pritchard.

It goes without saying that we are indebted to Pete Bradwell, Magda Read and Ashley Sweetland for speaking at AFIs Event which afforded us the opportunity to speak out on these concerns.

We are as indebted to the Big Lottery Funds Awards for All Scheme funding of AFI which was crucial in providing us with this vital medium.

Appendix C

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Special Needs & Inclusion, J. Harris, Letters Page, Jewish Tribune, 26th February 2007

Homesick Blues, Bob Dylan, March 1965

Facilitated Communications, J. Harris, Allergy Induced Autism, Autumn 2004; In Touch, Spring 2006

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Appendix D

Relevant Links

Major Political Party Website Policy Links

Conservative Party Website Policy link www.conservatives.com/tile.do?def=policy.listing.page

Liberal Democrat Party Website Policy link <http://www.libdems.org.uk/tenreasons.html>

New Labour Party Website Policy link www.labour.org.uk/ourpolicies

Other Political Party Website Policy Links

British National Party Policy <http://www.bnp.org.uk/policies/policies.htm>

Respect Party Website Policy www.respectcoalition.org/index.php?sec=39

Socialist Workers Party Website only (no Policy seems to exist) www.swp.org.uk

The Green Party Policy <http://policy.greenparty.org.uk/>

Interesting websites & information sources

Campaign for the Freedom of Information www.cfoia.org.uk

Corporate Culture Ltd, www.corporateculture.co.uk

Council of Ethnic Minority Voluntary Sector Organisations, www.cemvo.org.uk

Demos, www.demos.co.uk

Hear from your MP, www.hearfromyourmp.com

House of Commons & House of Lords www.parliament.uk (House of Commons and House of Lords)

Joshua's Planet, www.joshuasplanet.com

Knowledge Politics, www.knowledgepolitics.org.uk

New Economics Foundation, www.neweconomics.org

Sheffield Forum, www.sheffieldforum.co.uk

The Hansard Society, www.hansardsociety.org.uk

The Power Inquiry, www.powerinquiry.org.uk

They Work for You, www.theyworkforyou.com

UK Youth Parliament, www.ukyp.org.uk

Voluntary Action Sheffield, www.vas.org.uk

Write to them, www.writetothem.com

National Media

BBC, www.bbc.co.uk

Daily Telegraph, www.telegraph.co.uk

Guardian, www.guardian.co.uk

Independent, www.independent.co.uk

Observer, <http://observer.guardian.co.uk>

Times, www.timesonline.co.uk

