

Maximising Capacity and Valuing People

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Unless steps are taken to ensure that everyone of debatable capacity has access to information technology, the Government's stated goals of empowerment and inclusion for all will not be achieved.

To begin we will refresh your memory about the Learning Disability White Paper, "Valuing People". In it, the Government says the following precepts are central to providing services to people with learning disabilities (initially defined as individuals with an IQ lower than 70%, but people with Asperger's may also require special support to fulfil their potential).

1. Person is at the Centre
2. Family members and Friends are Full Partners
3. Person Centred Planning
 - Reflects the Person's Capacities,
 - Reflects What Is Important To The Person (Now And For Their Future)
 - Specifies the Support They Require To Make a Valued Contribution To Their Community
4. Person Centred Planning Builds A Shared Commitment to Action That Will Uphold The Person's Rights
5. Person Centred Planning
 - Leads To Continual Listening, Learning And Action,
 - And Helps The Person To Get What They Want Out Of Life

(the bizarre capitalisation is not ours but the Government's).

The idea is that individuals in care with very severe learning disabilities may still be capable of contributing to decisions about their lives, especially when people who know them well are encouraged to join in. This idea is also relevant to what is sometimes called "the Bournewood Gap".

Questions about medical consent and questions about administration of funds have been in obvious need of clarification for decades. Pressure from the Law Society on

the Government to clarify the law on mental capacity, and some suggestions as to how to do so, have at last resulted in draft proposals which after a consultation process are scheduled to become law in 2004. The issues raised by what is known as "the Bournemouth case" mainly concern a lack of protection under the law for people with learning disabilities who may not be able to communicate well enough to be deemed capable of giving or withholding consent. This became known as the "Bournemouth gap" (see table). Its identification as that resulted from an incident in which an adult with an ASD and severe learning disabilities had his normal morning routine severely disrupted, invoking a response in him, which led to his being incarcerated in a psychiatric unit from which his parents were unable to extract him for several months.

The "Bournemouth gap"

- "The gap allows a person who is unable to communicate or consent to treatment to be informally detained in hospital without any right to challenge that decision. From the Mencap website
- "The gap in the law became known as the Bournemouth Gap due to a landmark House of Lords case in 1998. In this case Mr L, a man with severe learning disabilities who cannot be named for legal reasons, was informally detained in hospital by Bournemouth Community and Mental Health NHS Trust for four months, following an incident at a day centre.
- "The law did not impose any checks and balances on Mr L's detention and his carers had no right to appeal against the doctor's view of the 'best interests' of the person who was detained, or to be consulted prior to his detention."

- from the Mencap website www.mencap.org.uk

Mental capacity and choice

Capacity to make decisions is recognised in the forthcoming legislation as fluctuating, hence potentially capable of being increased or decreased by circumstances. It may vary with the scale of the decision making: someone who may be perfectly capable of choosing which shampoo to use or which film to see may appear less capable of choosing whether Uncle Ben should sell the family home. It may vary with the topic under consideration, which can affect both knowledge and motivation. Decision-making capacity in a given individual varies most notably with variation in the emotional climate. Anxiety, anger, panic, demotivation, all these reduce intellectual capacity

The law will oblige everyone concerned to take all necessary steps to maximise decision-making capacity for those of debatable capacity. Only then should decision-making be devolved onto another person or persons. The legislators have considered what is involved in practical decision-making in some depth. However, we suggest they have left out of account at least two essential features of support in this area. The Draft Mental Incapacity Bill recognises that maximising capacity will include offering support in the following areas:

"Understanding information relevant to the decision; retaining information relevant to the decision; using that relevant information as part of the process of making the decision; communicating that decision (whether by talking, using sign language or any other means)"

We suggest that further basic needs also include both identifying and accessing relevant information and providing a calm and supportive emotional climate. Everybody needs all the above sorts of support at some stage of their lives.

Identifying and accessing relevant information

People with problematic decision-making capacity are likely to need sensitive support at the initial stage of identifying what information is needed, and constructive support in accessing it. The narrow focus of interest, which is typical in autism can mean that even the most apparently able people with the condition may miss relevant connections and implications. Relevant information must include advice about potential outcomes, since these are unlikely to be obvious to people with ASDs

For instance, at the Library or with friends, we can bring our understanding of a wide range of issues to bear in working out what specific information we need, and how to find it out. With little effort we access phone and phone directories, yellow pages, the right headings to search under; we think of the right questions to ask and the right people to ask them of. Few people with learning disabilities are likely to have the background education, the confidence, or the opportunities to enable such effective informal research. We all use the Internet too of course; Google has become one of our best friends - "anyone can Google". With a bit of help in identifying what to search for, there is no reason why people with learning disabilities, autism, dementia

or of problematic capacity for any other reason shouldn't be able to do that too. if you know how to find it all information found electronically can be digitally stored and accessed later.

Calm supportive emotional climate

Nobody is likely to make good decisions when they feel under pressure. Other people's questions and expectations are inherently pressurising, considered reflection might be more effective without that pressure. Having all the information available in searchable form at home, e.g. on a computer, so it can be revisited as often as needed, will contribute to the chances of a calm emotional climate for decision making. Not being under time pressure is also vital, not just for adequate processing to take place but to maintain emotional calm.

Understanding information relevant to the decision

Clear effective communication from whoever is providing support will be crucial to ensure good understanding of relevant information. Information will need to be plainly and carefully stated, using assistive communication when required, and it will need to be fully explicit and not assume background knowledge. Sufficient processing time must be given to the recipient; and information must be given in a written or graphic form in which it can be revisited as often as necessary.

Retaining information relevant to the decision

Everyone needs help retaining information: notes, photos, ground-plans: objects of various sorts which store information, files, folders, cardboard boxes or - best of all - computers. An easy to open easily browsed file with all the relevant information plainly set out in it can be placed on a computer desktop so it is also easy to find. It can be opened any time for consideration and re-consideration: the information is both preserved and accessible, i.e. it is effectively retained.

Using relevant information

Using relevant information as part of the process of making a decision should follow naturally once the information has been identified, acquired and stored for the purpose of making the decision, as above. Once it has been accessed and accessibly retained, information will be used so long as the individual who is being assisted in the process

of making the decision has understood both the information and its relevance, to grasp its relevance is to use it.

Communicating that decision

Communicating that decision (whether by talking, using sign language or any other means) will only be possible if one is accessing a recognised and accepted mode of communication. When communication problems are prominent special steps must be taken to ensure information flow. In some cases, with sufficiently supportive and sensitive care, communication may be far from standard and yet highly effective. That is why people who know someone well are encouraged to be part of the planning process in the Valuing People White Paper (see table above, point 2). Such people may recognise many forms of non-standard communication and be essential to the process. However, the more broadly accepted a means of communication is, the greater its potential social and communicative power.

Speech is the main currency of social exchange, so people who are not able to deploy speech are de facto excluded from many social situations; their views are likely to be devalued just because those views depend on another person to turn them into social currency. However, information technology is emotionally and socially neutral, and universally accessible in principle. For an example of the sensitive and constructive use of Information Technology in helping someone with severe autism who does not speak to acquire the ability to communicate her choices effectively, please see Appendix 1. At a computer, people who find the rapid exchange of speech impossibly demanding may be able to function as well as or better than most people. Anecdotal evidence (see *inter alia* www.autistics.org debate re: ABA), as well as the most recent research into facilitated communication (Andy Grayson), suggests that many people who do not speak do read, and can express their views effectively with a keyboard. For those who prefer or are used to dealing with visual symbols such as Widgits there is a variety of software, including email software which will translate from symbols to text and vice versa.

Max Cap Project: full IT provision for adults in care

- Computer
- Printer
- Scanner
- Camera
- Broadband Internet Connection
- Access to other Net users
- Email
- Net search facilities
- Word processing translation software (e.g. Makaton or Widget to/from text)
- Presentation software (e.g. Microsoft Powerpoint, etc)
- Graphics software
- Specially-adapted hardware (e.g. large, simple mouse)
- Minimum training in the above

Since according to the diagnostic criteria autism is a communicative disability, failing to provide accessible and acceptable modes of communication including email may well be discriminatory. Failure to provide adequate channels of communication may contravene the Disability Discrimination Act and the Human Rights Act, as well as making a mockery of Valuing People and the goals of coming incapacity legislation. IT can contribute in many ways to individual autonomy, having the potential to find, store, retrieve, and display relevant information about people's personal histories, relationships, goals, and interests in a way they can control. Computers and their peripherals offer great possibilities for building up a store of treasured, easily shareable, images. Access to email means people can exchange messages and pictures with family and friends with minimum effort.

As always, there are potential undesirable consequences, some of which can easily be foreseen and managed. The equipment must be preserved for service users – adequate provision of IT for staff use is also necessary. Staff working in the context of good management practices will usually have access to an office computer. The equipment will also require to be maintained. Another possibility is that service users will access chat-rooms and/or seek out pornography. We would advocate that such

use should be monitored but not prevented unless pursuing matters of serious concern such as suicide or illegal sexual activities. It may sometimes be necessary to intervene. However, the concept of inclusion must permit any adult in care to pursue legal sexual interests on the Internet.

Unless the Government takes positive steps to ensure that everyone with learning disabilities or dementia have access to information technology its sincerity about maximising either individual autonomy or participation will be in doubt. Such steps might even have ameliorated the awful incarceration and isolation experienced by Mr L in the Bournewood case. The UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities is proceeding towards ratification, and it is also highly relevant to the rights of people with cognitive and communicative disabilities. For example, its preamble refers to

“Recognizing the importance of accessibility to the physical, social and economic environment and to information and communication, including information and communication technologies, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms”

Several of its Articles are equally applicable to the argument in this paper, the whole of the Draft Convention can be found online; we have reproduced a selection of key points in Appendix 2.

We suggest that Her Majesty's Government should take prompt action to assist the fulfilment of legal obligations, which it has imposed, or will impose. That action should include extensively subsidising or otherwise supporting all service users in care (geriatric, mental health and physical disabilities as well as autism and learning disabilities) to acquire the necessary technology. Care standards legislation should oblige provision of access to information technology for all service users. The Government should assist and promote inexpensive broadband deals to all care providers. Boredom and disempowerment cause “challenging behaviours” (Zarkowska and Clements, 1991; Emerson et al, 1993). The high costs of these in both emotional distress and staff time mean that investment in IT would ultimately greatly reduce the costs of service provision. Concepts of respect, autonomy and

especially inclusion will remain a sham for those in care unless the steps outlined above are taken.

Reading

Emerson E, Magill P, Mansell J. (eds.) (1993) *Severe Learning Disabilities and Challenging Behaviours*. London: Chapman & Hall.

Zarkowska E, Clements J. (1991) *Problem Behaviour In People With Learning Disabilities - A Practical Guide to a Constructional Approach*. London: Chapman & Hall.

Where to find the legislation, proposed or actual

1995 Disability Discrimination Act

<http://www.disability.gov.uk/dda/>

1998 Human Rights Act – its articles are listed at

<http://www.hms.o.gov.uk/acts/acts1998/80042--d.htm#sch1>

2001 Valuing People A Strategy for Learning Disability for the 21st century

<http://www.valuingpeople.gov.uk/papers.htm>

2004 Mental Capacity Bill

<http://www.publications.parliament.uk/pa/cm200304/cmbills/120/04120.i-vi.html>

Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities

www.un.org/esa/socdev/enable/rights/ahc3reportadv.htm

Appendix 1

A short case study from a day service equipped with Multimedia

“Sue finds it difficult to choose her own activities. We have to take her to different places, social events, or activities in the community several times before assessing if she likes going there or not. In terms of the swimming session, I would film (with Sue’s agreement) and take pictures of her activities. Before going each week I would show Sue her Object of Reference (swim suit), and reinforce her understanding of the

activity by showing the picture of the leisure centre. After a couple of weeks, I would then place two pictures out in front of Sue, one of swimming, the other of Syon park, Sue will then choose the activity by touching the picture of her preferred place. The one Sue doesn’t want to go to she will push away.

“For nearly 1yr I had been filming Sue, on how she was making progress. I felt it was important for Sue to bring something of her own to her meetings, also it would give everyone a chance to see Sue’s likes, dislikes, needs, wants. Through the help of the Multimedia Profile classes, and months of encouraging Sue to use a communication switch, I was able to put a short film together for Sue and other people in her life to see the many changes she has experienced. The film was finally shown at Sue’s review with Sue’s consent. We used a laptop and connected the switch to the laptop. The film was on DVD, which was compatible to the laptop, we were using. This was great for Sue, she was able to introduce herself and open the meeting

“When Sue was ready, she would press the switch to show the next clip. Just before the end of the film, Sue pushed the switch away, and went to sit across the room to watch the rest of the film. While the film was being played, everyone was shocked to see the amount of things Sue can now do. All conversation was centred on her, it had moved away From what we think to what we see and know. The first comment that was said when the film had finished, was from a member of her family, she said it was ‘the first time she had ever seen Sue sit down and not hit herself throughout her review meeting’, they never thought they would see this day.”

When this programme of empowerment began, Sue used to spend most of every day screaming, spinning, self-injuring, and hiding in the day centre’s toilet for hours on end. She now goes swimming weekly with a swimming club made up of people of her own age group, and when she wants to “hide” she goes to the music room and listens to classical music for a while.

Appendix 2

Excerpts and footnotes from Draft UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities

For the complete document please see
www.un.org/esa/socdev/enable/rights/ahc3reportadv.htm

In Preamble

(q) Recognizing the importance of accessibility to the physical, social and economic environment and to information and communication, including information and communication technologies, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms

Article 3

Definitions

“Accessibility”...

“Communication” includes oral-aural communication, communication using sign language, tactile communication, Braille, large print, audio, accessible multimedia, human reader and other augmentative or alternative modes of communication, including accessible information and communication technology.

Article 4

General obligations

1. States Parties undertake to ensure the full realization of all human rights and fundamental freedoms for all individuals within their jurisdiction without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- ... (e) To take all appropriate measures to eliminate discrimination on the ground of disability by any person, organization or private enterprise;
- (f) To promote the development, availability and use of universally designed goods, services, equipment and facilities. Such goods, services, equipment and facilities should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities.

Article 5

Promotion of positive attitudes to persons with disabilities

1. States Parties undertake to adopt immediate and effective measures to:

- (a) Raise awareness throughout society regarding disability and persons with disabilities;
- (b) Combat stereotypes and prejudices about persons with disabilities;
- (c) Promote an image of persons with disabilities as capable and contributing members of society sharing the same rights and freedoms as all others and in a manner consistent with the overall purpose of this Convention.

Article 9 Equality under the Law

... (d) Ensure that persons with disabilities who experience difficulty in asserting their rights, in understanding information and in communicating have access to assistance to understand information presented to them and to express their decisions, choices and preferences, as well as to enter into binding agreements or contracts, to sign documents and act as witnesses...

Article 13

Freedom of expression and opinion, and access to information

States Parties shall take appropriate measures to ensure that persons with disabilities can exercise their right to freedom of expression and opinion through Braille, sign language and other modes of communication of their choice, and to seek, receive and impart information, on an equal footing with others, including by:

- (a) Providing public information to persons with disabilities, on request, in a timely manner and without additional cost, in accessible formats and technologies of their choice, taking into account different kinds of disability;
- ... (e) Promoting other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- (f) Encouraging private entities that provide services to the general public to provide information and services in accessible and usable formats for persons with disabilities;

Article 19

Accessibility

1. States Parties to this Convention shall take appropriate measures to identify and eliminate obstacles, and to ensure accessibility for persons with disabilities to the built environment, to transportation, to information and communications, including information and communications technologies, and to other services, in order to ensure the capacity of persons with disabilities to live independently and to participate fully in all aspects of life. The focus of these measures shall include, inter alia:

.... (b) The development and remodelling of public transportation facilities, communications and other services, including electronic services.

Article 21

Right to health and rehabilitation

... (f) Encourage research and the development, dissemination and application of new knowledge and technologies that benefit persons with disabilities...