



Afasic's response to *Improving the Life Chances of Disabled People* (Interim Analytical Report)

Afasic is the UK charity which represents children and young adults with speech and language impairments, working for their inclusion in society and supporting their parents and carers. Afasic is delighted to respond to this consultation on behalf of the people we represent.

Afasic welcomes this report which reflects a thorough understanding of many of the issues that currently impact on people with disabilities, and we are pleased that the strategy unit is attempting to address this subject.

Afasic welcomes the emphasis in the report on adopting the social model of disability (pp. 32 - 34). However, the report fails to acknowledge some of the practical implications of doing so:

1. The task of removing barriers to 'disabled people's inclusion in society' (p. 34) will entail considerable costs and changes in both society's attitudes and infrastructure. In particular, it is likely to be very expensive to make this aspiration a reality for people with more severe disabilities. Yet the report does not indicate that any more funding will be forthcoming. The promises that the government will 'provide a level of support which balances cost sharing in a predictable and fair way' (p. 4) and 'balance competing priorities and values' (p. 37) do not inspire confidence, suggesting, as they do, that funds will remain strictly limited. What is needed is a detailed and costed explanation demonstrating exactly how the task of removing the barriers will be funded and achieved, and how individuals with disabilities, or their families, can access the support they require.

The report seems to suggest that better co-ordination of support (e.g. p. 38), together with greater provision of lower-level support will avoid or reduce the need for high-level support. For example, page 71 appears to suggest that educating more children with special needs in mainstream or local special schools would save on the cost of special schools, especially residential special schools (which cost '2 - 3 times' as much as day schools).

This assertion does not take into account the fact that some children have very high or specialised levels of need that can only be met in special schools and sometimes only in highly specialised residential schools. If they were educated locally, they would still have those needs which would have to be funded and it would often cost more to provide the level of support the child needed in a local mainstream or special school because there would no longer be the economies of scale involved in grouping children with similar needs together.

The report seems to suggest that if these children received earlier intervention they would not in later years require such intensive support. While this might be true in some cases it certainly would not be in all. Some children are born with, or acquire, severe disabilities that will always require very high levels of support.

2. The social model of disability is not always clearly understood, and the way that it is interpreted can have adverse consequences for people with disabilities. For example it can be used as a justification for not giving a medical diagnosis, yet without a detailed diagnosis, it is not always possible to understand the nature of the barriers people with disabilities face, and so find ways of overcoming them.

An issue that concerns Afasic is the government's current policy of devolving more and more SEN funding to schools and reducing the number of statutory assessments and statements. What this means in practice is that increasing numbers of children with speech and language impairments are not receiving the specialist support they actually need. Teachers do not have the expertise to identify speech and language impairments, or assess the children's learning needs, and few are able to adapt their teaching to meet the children's needs without assistance. This requires the input of, respectively, speech and language therapists, psychologists and specialist teachers with expertise in teaching children with speech and language impairments. Most schools do not have such staff on-site, and may find it hard to access them. More seriously, many teachers do not know when they need to seek such help for children in their care. Skilled assessment is needed to distinguish children with specific speech and language impairments from children who are slower learners or who have general or specific learning difficulties.

The result of all this is that many schools are tending to use their SEN funding to pay for extra learning support assistants and are grouping all children with SEN together and treating them in much the same way, so we are moving away from a system that at any rate aims to provide high-quality support to meet the needs of the individual child's SEN, to a generic SEN support structure which does not really meet anyone's needs properly, which is quite unsatisfactory. Afasic is concerned that this report, with its reference to 'minimum...services' (p. 42), is likely to continue the trend towards generic services for people with disabilities, rather than services tailored to individual needs.

A strict adherence to the social model of disability can also lead to assumptions that, with a few changes or a bit of support, there is nothing people with disabilities cannot do. Sadly, for at least some people with disabilities, even very high levels of support will not enable them to do all that most of us take for granted. This should not be forgotten, and care needs to be taken when advocating the social model of disability, to articulate it carefully, so that the needs of all disabled people are recognised and acknowledged. For example, the drive to enable as many disabled people as possible to secure employment, should not lead to the marginalisation of anybody with a disability who is unable to do so.

There is still a long way to go before the social model of disability is accepted across society as a whole. As the report itself points out (on page 58), ante-natal screening is widely supported and actively promoted on the NHS in a way that surely would not happen in a society which had 'no stigma, prejudicial attitudes or discrimination' (page 47) towards disability.

What this report does not identify is that the real problem with the current system of support for people with disabilities is that it is not adequately policed. While this remains the case, cash-strapped local authorities and health services will continue to fail some of the most vulnerable members of our society.

Another important issue that this report does not consider in any depth is what constitutes a disability. Modern society has become much more complex than it was only 2 - 3 generations ago. People now have to manage in a technology and information-driven world that demands much higher-level skills than are needed in simpler societies. This means that increasing numbers of people who would not have been described as 'disabled' in the past, and might not fulfil the criteria for disability now, are nevertheless reaching maturity without the necessary skills to cope successfully with adult life. The outlook for them is bleak. Social exclusion, and in some cases, a life of crime are likely to follow. Many of the children and young people Afasic represents fall into this category. Many of them have substantial help at school, but on reaching adulthood find that they are not considered 'disabled' and must manage without support. Yet, many of them still have significant difficulties with communication, literacy and numeracy, social and organisational skills, and so struggle to cope with the demands of modern adult life. We need to recognise that the demands of our modern society mean that many people who would not have been considered 'disabled' in the past, are now in fact functionally disabled and need appropriate support to cope with modern adult life. It is interesting to note that the types of disability discussed in the sections about children and adults in the report differ greatly. Yet the children do not go away. They grow up, and in many cases still retain their impairments which, without support, render them 'disabled'.

As Afasic represents just children and young people, I shall add a few comments on the sections applying to them.

Early Years

The main problems here are:

- Insufficient funding within the system, so that there is always a temptation to avoid or delay providing intervention if possible.
- Services for children with disabilities are always an 'add-on'. We need to move to a situation where planning for children in general includes the needs of children with SEN/disabilities.
- Support for children with disabilities is most commonly accessed through the education authorities, who are able to 'wash their hands' of the children when they reach 16 or 19. Consequently, there is no real pressure on them to ensure they provide the right support. Also, education services tend to think in terms of enabling children to manage at school, and not about equipping them to cope with adult life. This affects the type of support they provide, and helps to explain why so many children are not given special training in the essential social, communication and life skills that they need if they are to make a successful transition to adult life.
- We entirely agree that there is insufficient speech and language therapy, and other therapies such as occupational therapy. It also needs to be borne in mind that some children will require speech and language therapy throughout their school careers and into adult life. Where this is the case, they must be able to access it. We are concerned by the implications of the comment on page 74 that 'National minimum standards would deliver greater clarity on what families with

disabled children can expect from the state, and on what basis. This could include services such as speech and language therapy.' Some children need more speech and language therapy than others, and the provision must be based on the individual child's need, not a standard generic package. The lack of speech and language therapists should be addressed by the following measures:

- paying them a professional salary. This means looking very hard again at the implications of the proposed **Agenda for Change**, which if implemented in its current form will mean the NHS losing most of its most senior and experienced therapists. This will leave the NHS quite unable to meet the need for speech and language therapy, and will seriously damage the structure of the profession within the NHS, as there will be insufficient senior therapists to manage the service and oversee more junior and newly-qualified therapists. This will severely damage the skill-base within the profession.
- treating them as professionals and enabling them to do the work they were trained for, rather than expecting them to 'manage a caseload'
- train more speech and language therapists, especially men, and make greater efforts to retain or attract back women who take career breaks to have children.

From Childhood to Adulthood:

This transition process often does not work well at the moment for young people with speech and language impairments. Adult services generally do not seem to be aware of their needs and provide little if any support for them. This means that our young people, many of whom have substantial support through their school years, are suddenly expected to cope with little or no help when they leave school, despite being often ill-equipped to do so. The following are particular issues:

- Speech and language therapy, tends to disappear at this stage if it has not already done so. Although FE colleges can purchase speech and language therapy, very few do so. This is probably due to ignorance about speech and language impairments and the needs of the young people Afasic represents.
- There are few, if any, college courses or support services designed specifically for young people with speech and language impairments. The choice is usually between standard college courses with or without whatever support is available, or, if they cannot cope with those, courses for students with learning disabilities.
- Transition planning at school is often inadequate. Often, it only identifies the 'next step' and does not consider any other issues standing in the way of a successful transition to adult life. Social services rarely become involved with young people with speech and language impairments, as they usually only attend transition reviews of children attending special schools, which seems indefensible given the trend towards inclusion. Connexions Advisers do not always understand the issues affecting young people with speech and language impairments. However, where they are helpful, they seem to have little power to achieve anything on behalf of their clients. As ever, the decisions are ultimately made by the authorities (local councils, learning and skills councils or health services) who have to fund any support.
- Securing and retaining employment can be very difficult for young people with speech and language impairments because of their poor communication, organisational, social, literacy and numeracy skills. However, help is often not forthcoming to help them find work. Jobcentre staff, including trained disability advisers, often do not seem to understand the nature of their difficulties, and are

unable to help. Clearly, they need more training. It must also be acknowledged that some young people with disabilities, including some with speech and language impairments, are unable to work or even to live independently without support. Where this is the case, it is vital that they receive the support they need. The goal of employment and independent living for everyone (pages 80 and 83) while admirable are not achievable for everyone and should not mean that anyone failing to achieve this is marginalised, or given a low priority.

P. 102: Afacic would like to see the following improvements in the transition process:

- More training of Connexions staff in disability issues and perhaps specialist advisers for young people with (different types of) disabilities.
- Education at all ages but especially at the 14 - 19 stage needs to put more emphasis on the acquisition of fundamental skills, not only adequate literacy and numeracy but also functional communication, inter-personal and independence skills. These are essential for adult life and most young people without disabilities acquire these skills with little conscious effort, but many young people with disabilities need to be taught them systematically and given the chance to practise them within a peer-referenced group.
- In order to ensure that young people receive the support they need from health and social services, we would recommend introducing a legally-binding contract along the lines of a statement of special educational needs, setting out exactly what help will be made available.

Alison Huneke, Helpline Manager, 12.8.04