

Michael Cooke
Office for Disability Issues,
Department for Work and Pensions,
The Adelphi,
1–11 John Adam Street,
London,
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cc. Gerald Howarth MP

8th May 2007

Dear Mr Cooke,

Response to Consultation Document
Equality for disabled people – How will we know we are making progress?

I attach our response to your request for views about equality for disabled people.

Parity For Disability is a charity whose objectives are focused on the tenets of Equality, Rights and Dignity in providing services for children and adults with profound and multiple disabilities and supporting their families and carers. All the children and adults who use our services have complex and multiple disabilities; with one or two exceptions all have a very significant physical disability and a high learning need. Many have additional sensory impairments; a high proportion are non verbal using alternative means of communication; for many this can be as subtle as eye movement.

As a result of the very high level of disability of our service users, they are not able to participate in consultations such as this. We are, consequently, concerned that needs are not being taken into account and that the disability equality debate is being led mainly by disabled people who are very vocal and are able to speak quite legitimately about their own lived experience of disability and discrimination. These cannot, understandably, explain the experience and needs of people with profound and multiple disabilities. We believe our concerns about adequate representation can be demonstrated when one reads “Valuing People A New Strategy for Learning Disability for the 21st Century”. Just two paragraphs are devoted to our client group compared to several pages devoted to the needs of children and adults with autism yet according to the government’s own statistics there are approximately 500,000 people with multiple disabilities in the UK. In a similar way the needs of our client group are briefly discussed in an appendix of – “Improving the Life Chances of Disabled People” without an in depth examination of their needs.

Our experience of working with families tells us that there is a lack of facilities for profoundly disabled people. Indeed, the need for specialist services for people with profound and multiple learning disabilities (PMLD) is well documented. Our own research in 1988 proved the need and led to the development of our current services.

This has since been substantiated by the increasing number of people seeking our support. However, additional services have not been forthcoming and a desperate need has been expressed through reports nationwide.

In 2001 Mencap documented the experiences of parents of children and adults with profound and multiple disabilities in "No Ordinary Life". This was followed by "Valuing People with Profound and Multiple Disabilities" a response to the Government's "Valuing People" white paper by the PMLD Network. The Government's own report "Valuing People, the story so far" in 2005 records that people with Profound and Multiple Learning Disabilities still face discrimination and barriers to equality. Another Government document "Improving Life Chances for Disabled People" highlights the increasing numbers of children with complex needs, echoing the trends expressed by head teachers of our local special schools and proving that even more services will be needed in the future. The All Party Parliamentary Group on Learning Disability discussed the rights of people with PMLD in 2005 and noted the need for specialist services. Time and again the needs of people with multiple disabilities and their families are neglected and not properly understood. Personal stories and experiences are documented on internet forums such as the PMLD Network where the same problems are expressed year on year.

To add to this, other forms of support are being eroded. Two examples locally are of Scope withdrawing their grass roots fieldworker services and the closure of BDIN, the Berkshire Disability Information Network. Parity has the ability, skills and expertise to help meet the needs but is consistently hampered from developing its services because, in spite of government policy, statutory services are still largely not purchasing services on a full cost basis. This absorbs considerable time and expertise that should be devoted to the provision of services

We hope you will find our response helpful, it does represent our very focused views on the equality and rights for our "students" which have been formulated over a considerable period of time from ongoing consultation with our service users, their parents and carers.

A brief overview of Parity's work is attached.

Yours sincerely

Paul Roper
Chairman

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About Parity For Disability

Parity For Disability is an independent charity initially founded in 1953. It is a company limited by guarantee and registered as a charity with the Charity Commission.

For the last 18 years the charity has, within its objects, focused its aim to provide quality services to children and adults with profound and multiple disabilities. It also supports them, where appropriate, by providing assistance to the parents and carers, for example, by providing information and advice.

The philosophy of the service has the tenants of Equality Rights and Dignity. The charities mission statement is “Excellence in Services and Support for People with Multiple Disabilities and their Families”.

Parity for Disability service provision consists of:-

- Two day services
In these it provides a one to one keyworker/student ratio. Each student has an individual programme designed to enable that student to reach their potential. Physiotherapy is provided on a continuous basis with the physiotherapist advising the keyworker on the programme designed for each student. Speech and music therapy are provided where appropriate.
- Music therapy service
This service is primarily concerned with children and adults whose disability is mainly on the autistic spectrum and have great difficulty in relating to another person.
- Teenage activity scheme
This is a scheme run in the Easter and Summer holidays for teenagers on vacation from special schools. We employ their able-bodied peers to act as enablers. We encourage the disabled students to make choices and provide resources to ensure these are acted upon.
- Where we appropriate outreach support for the student.
- Advice and support to families.

Parity For Disability

Response to Consultation Document

Equality for disabled people – How will we know we are making progress?

CONSULTATION QUESTIONS

WHAT DOES EQUALITY FOR DISABLED PEOPLE MEAN?

Q1 What does equality for disabled people mean to you?

A general approach to defining equality is to being able to do those things which non-disabled people take for granted. In many respects we agree with that however this is usually referenced in terms of accessing employment, transport and the general environment. We feel that a more general definition of equality would be “Quality Of Life”.

With very general indicators quality of life is a concept that is applicable to people with varying levels of disability and is also totally applicable to people who are non-disabled. At a very specific level the indicators could be quite different for people with different levels of disabilities. For example someone with a physical disability would expect to be employed consequently would expect the barriers that hinder that objective to be removed. However, in comparison, a person with profound and multiple disabilities might expect a meaningful varied structure to their daytime and evening activities.

Q2 Can you describe any examples of equality for disabled people you have experienced or know about?

We believe that Parity For Disability service provision is a good example. It works with children and adults with profound and multiple disabilities.

This means that all our services users have very significant physical disability, a high level of learning disability, severe communication difficulties, often with additional sensory impairments and conditions such as epilepsy. They need assistance with moving and all aspects of daily care.

Many of the young adults with profound levels learning need have left special school aged 19 with no access to further education or opportunities. Other services provide only basic care facilities with little or no intellectual stimulus. Parity's service provides a one to one service and an intellectual stimulus helping this group of disabled people to reach their potential.

The tenets of service provision is equality rights and dignity. We work with each disabled person to help them achieve their potential and believe it a fundamental part of the provision that they are helped to make choices and these are acted upon.

The level of physical disability requires access to physiotherapy and hydrotherapy to alleviate many of the accompanying and constant painful conditions. Since this is an ongoing requirement it is not available from the NHS which only provides such therapies on an interventionist basis.

Many of our service users have very significant communication problems. Some use communication aids but for many, communication is extremely difficult and can be as subtle as interpretation of eye movement. Speech therapy is vital, not to help them speak, but to establish a basic means of communication. High staffing ratios are vital to interpret and act upon these communications.

We provide a service for children and adults who have a very significant disability on the autistic spectrum, a brain injury or other conditions sometimes genetically based. Typically they find it difficult to relate to another person or express their frustration and anger associated with their disability. Music therapy uses music to help this group of people bridge this huge chasm. It is a very slow process and requires highly qualified music therapists.

Parity For Disability services provisions consist of two day centres with staffing ration of one to one, a music therapy scheme and a teenage activity scheme.

Q3 Do you think there should be a single measure of equality, or that we need to measure progress on different aspects of disabled people's lives?

We do not believe there can be one single measure of equality, however, as described above we believe there can be a single concept that is equally applicable to both disabled and non-disabled people but it has to be defined by general measures that would also be equally applicable but the indicators of these measures would be different depending on the person's specific disability.

Q4 If you think we need more than one measure, what do you think should be the five main features of equality that are measured?

Physical well-being

Quality and adequacy of care assistance

Access to appropriate therapies. Many people with profound and multiple disabilities experience significant discomfort associated with their condition but are not able to access physiotherapy because the NHS provision is only an interventionist service.

Free speech

Removal of barriers that prevent a disabled person from having the same ability to communicate and express views as a non disabled person.

For some disabled people this will be the removal of physical barriers and prejudice; for others it could be access to an appropriate type of advocacy or facilitation by an enabler if the disabled person has speech which is difficult to understand.

Many people with profound and multiple disabilities are non verbal and access to speech therapy is essential for development of alternative communication systems.

Some people with very profound levels of disability communication could be very subtle and complex, for example simple eye movement. In these circumstances long term and specialist advocacy would be needed. For others who are also on the autistic spectrum and have significant problems relating to another person, music therapy can provide a alternative means of communicating frustrations and feelings.

Intellectual stimulus

Ability to access further education opportunities whether this is vocational or in life skills.

Many colleges still have significant difficulty in facilitating students with high support needs wishing to pursue mainstream courses. Distressingly, many colleges have abandoned specialist courses designed for people with profound level of disability on the basis of cost.

Ability to access employment on an equal basis with their comparable peer group. Whilst many people may regard employment as a means to an end providing financial recourses to sustain essential and discretionary lifestyle choices; others, however, consider it is also important because they find it fulfils an intellectual need and requirement to demonstrate achievement.

Employment, is of course, not an option for the vast majority of people with profound and multiple disabilities yet they have similar, if not identical intellectual needs albeit, perhaps, at a different level. They should have a right to have services and programmes that meet those needs.

Accessing society.

Physical barriers preventing access to buildings, transport and services

Overcoming prejudice associated with profound disability, for example being denied access to public places because of sensitivity of non-disabled people with profound disabilities and associated consequences such as drooling.

Sufficient financial resources to sustain an adequate quality of life.

Fair remuneration from employment

For people with profound disabilities sufficient income to purchase services providing intellectual stimulus over and above those costs associated with basic living.

How should we monitor progress towards equality?

Does the number of people with profound and multiple disabilities seen in society reflect the incidence of this level of disability.

The number of profoundly disabled people able to access long term advocacy.

The number of profoundly disabled people who are able to access sufficient financial support from statutory services to provide them with services that provides an acceptable quality of life.

CONSULTATION QUESTIONS ABOUT EARLY YEARS AND FAMILY SUPPORT

Q5 **What aspects of life for disabled children and their families do you think it most important for us to monitor over time?**

Independent support and advocacy

Support for families at the time of diagnosis help with understanding the prognosis guidance to organisations that will give specialist information about the diagnosed condition.

Many families experience of having a child with a disability is that at a time when they are struggling to come to terms with problems associated with this they find they are engaged with a battle with the statutory services to get the funding and services they require to support the child and the family. In essence the family with problems has additional problems loaded on them by the statutory services just at the time when they need the maximum support.

Q6 Which three measures do you think would be the most important indicators of equality in this area?

Access to specialist advice and facilities eg:-

- at the time of diagnosis.
- keyworker system; Team Around The Child etc
- ease of access to appropriate equipment, adaptations etc

Availability of respite care.

Adequate financial support.

CONSULTATION QUESTIONS: TRANSITION TO ADULTHOOD

Q7 What aspects of transition to adulthood for disabled young people do you think it most important for us to monitor over time?

Being aware of numbers of young people so planning is possible

Agreed responsibilities – who's going to do what

Maybe avoiding too much transition (e.g. from school, from doctor, from social services team) at the same time

Monitoring progress to make sure young people aren't getting lost in the system (or falling out of the system)

Choice in housing options and support to access these.

Support to enter employment and training schemes

Access to intellectual stimulus post schooling and further education. whether this is vocational or living skills.

On going access to services available as a child such as physiotherapy and speech therapy where an alternative communication system is used including ongoing support for alternative communication systems. Most importantly support to make choices.

Access to long-term advocacy

Q8 Which three measures do you think would be the most important indicators of equality in this area?

Reports from schools for at least the first two years (preferably five years) after leaving school
Availability of ongoing support for alternative communication systems.
Access to long-term advocacy.

CONSULTATION QUESTIONS ABOUT EMPLOYMENT

Q9 What do you think are the most important issues in respect of employment that we ought to monitor?

Q10 Which three measures do you think would be the most important indicators of equality in this area?

CONSULTATION QUESTIONS ABOUT INDEPENDENT LIVING

Q11 What do you think are the most important issues in respect of independent living that we ought to monitor?

We wonder whether independent living is the best concept since the term can appear to be very limiting and appears to be centred around the concept of a person with a physical disability living in a house of their own choice with adaptations and support. Many disabled people have to qualify the term to show its wider meaning. Choice of residential options for people with profound and multiple disabilities. The more likely provision would be a small independent living within a small residential unit of perhaps three or four people. Perhaps the better concept would be self-determination where people can live in a manner that they wish and be supported to make choices about that type of living option and their life style in it.

Q12 Which three measures do you think would be the most important indicators of equality in this area?

Access to long term advocacy
Sufficient financial support
Privacy within a group home

CONSULTATION QUESTIONS ABOUT AREAS NOT ALREADY COVERED

Q13 Are there any other issues in respect of disability equality that we ought to monitor?

Lifespan
Society's general awareness and attitude to disability.

Q14 Which three measures do you think would be the most important indicators of equality in this area?

Number of schools undertaking disability education.
Quality of disability education in schools.

Inclusion of people with disabilities in media (specifically TV) programmes but outside of sport and comedy.