

DLAAB

Disability Living Allowance Advisory Board

NEWS & UPDATE

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Topics for Future Issues

- ◆ Aphasia
- ◆ Epilepsy
- ◆ Extended stress after amputation
- ◆ Falls in older people
- ◆ Downs Syndrome
- ◆ Stereotypes

DM's suggestions for topics welcome. Please contact us.

Introduction by the Chair

Hello Everyone

Welcome to this edition of DLAAB Up-date and news. Often we just take for granted the fact that we can jump on a train and travel anywhere we like. For Clair it isn't quite so easy as you will read in her article.

Occupational Therapy is so important in seeking as independent a life as possible and in the second article Judith describes the occupational therapist's very important role.

I hope you will find both articles helpful and enjoyable.

As always we welcome your views and ideas for this newsletter.

With best wishes

Anne

Anne Spaight
Chair DLAAB

Access with a disability

Clair Poole

This is a subjective article about some of the practical difficulties involved with travelling as a person with a disability, what the Disability Discrimination Act covers and what to look forward to. All examples are factual and experiences real.

How much of your day-to-day life – if you are a person without a disability - requires you to ask total strangers for physical assistance, plan ahead, make phone calls and book appointments? Going to work, socialising, shopping, attending a concert or popping in to Town. All these activities can be done on the spur of the moment. You could drive (maybe worry a little about parking), catch a bus, take a taxi, a train, the tube or walk and, should something unforeseen happen you could switch from one type of transport to another without too much difficulty.

Taking a plane to travel on holiday or for business needs an element of forward planning but only so far as booking tickets and arranging schedules.

For a person with a disability it requires a great deal of planning to travel successfully even for the simplest of these activities.

The Disability Discrimination Act 1995

The Disability discrimination Act (DDA) defines a disabled person as: Someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities

- In December 1996 employment was covered by the DDA with further additions in 2004.
- In October 1999 service providers had to make 'reasonable adjustments' for disabled people and in October 2004 this was extended to the physical features of premises to overcome physical barriers to access.
- In 2002, 2003, 2005 and 2006 laws relating to education came into force.

Service providers.

There are some areas excluded or treated differently under DDA such as the use of certain forms of transport. Transport termini (stations, airports etc) and some facilities related to transport – such as booking tickets – are covered by this section of the Act and will have to take reasonable steps to improve their services.

However, taxis and some public transport vehicles are dealt with in a different section of the Act.

Planes and ships/ferries are completely excluded from the Act.

Perceptions

Most people agree that disabled people should be able to live as full a life as possible. Now that legislation is in place there is a feeling that the rights of disabled people are equal to others in society.

There has been widespread publicity surrounding the changes to be made to enable disabled people access to facilities. Ramps, handrails, Braille on lift buttons and induction loops are now familiar in our environment. Signs outside small shops and cafes saying 'ramp available' are common.

Public transport is widely perceived as being accessible.

Would it therefore be a surprise to find:

- A group of deaf people were refused permission to take a flight as they were all travelling together.
- The DDA does not cover aviation and the pilot has authority to restrict the carriage of persons with restricted mobility.

- A wheelchair user arrived at a station - having pre-booked assistance and checked her wheelchair would fit on the train - to find that the doorway to the First Class carriage was actually too narrow. She was given the choice of not travelling or crawling to her seat.
- The DDA gives train companies until 2020 to comply and at present about 50% of rail vehicles have some form of exemption from accessibility regulations.
- A 17-year-old girl was refused entry to her local nightclub on the grounds that her crutches could be used as weapons.
- The Equality and Human Rights Commission (formerly the Disability Rights Commission) is now looking at this case.

The Adventures of an Intrepid Wheelchair User.

When travelling by train I need to book assistance 24 hours in advance and arrive at the station 30 minutes before departure time. If things go as planned I am assisted onto the train and the guard makes sure I have access to refreshments. There is a nearby accessible loo and I can relax for my journey. On arrival I will be assisted down a ramp and taken to a waiting taxi.

I arrive at the venue for my meeting having been assured that the premises are accessible. All proceeds well and I enjoy an uneventful journey home.

Or

I arrive at the station 30 minutes early (for the 5.45am train). No one is in sight. I sit in my chair on the freezing cold platform looking into the train. After 25 minutes someone rushes up, produces a ramp and loads me on with minutes to spare. The guard makes his one appearance to check my ticket, apologises for the door to the accessible loo being wedged open and the heating not working in the carriage and away we go. There follows four hours with no refreshments and no 'refreshment break' either. Arriving at my destination I wait for assistance. None comes. I am in the way of the cleaners rushing up and down unable to get their trolleys past me. A sympathetic passer by offers to get help and a few minutes later I am bundled off the train on a ramp that is not touching the ground as alterations are taking place and the platform isn't wide enough. I try not to think about the drop onto the tracks, say 'thank you' to the harassed staff member and head for the taxi rank via the disabled loo.

On arrival at the accessible venue (a well known London hotel) the driver has to park illegally to drop me off. I wheel myself over uneven paving to the front of the building (where I had been asked to wait) to be greeted by a member of staff who takes me to the disabled entrance. This involves going back to the back of the hotel, balanced on the narrow pavement on one wheel, through a friendly group of

smoking staff and into the building. Once through the narrow doorway we negotiate a foot drop to the left and then pass through a maze of corridors, under an array of pipes and a section of suspended ceiling that is falling down to a lift that I can only fit in with the footrests of my chair removed.

At the end of the day I arrive at the station an hour and a half before my train is due to leave. At the assisted travel office I ask if I can take an earlier train which is due to depart in half an hour. There is already one wheelchair user booked on the train so no space for me.

Once I arrive at my destination I await my assistance having double-checked with the guard that they are expecting me. No one in sight. This time a passenger who was travelling further got off the train to find assistance. I was greeted with a 'we didn't know you were coming you should have booked' and a disapproving look.

Being a wheelchair user I get to see many things hidden from the public eye, from the 18th century graffiti in the service lift of a famous store to the airport departure lounge on an incoming journey. In one hotel my disabled room had a disabled bed...it only had three legs. I have found myself wedged between the queue barriers and the sweet display in Marks and Spencer and my chair has been draped with underwear unknowingly hooked from displays in a clothes shop.

I have seen the best side of the public as individuals have offered help in many ways on many occasions. I have had shop assistants offer to bring an entire range of clothing down from upstairs, as they had no lift. On the flip side I have been patronised, talked over and had doors closed in my face. People who would rather stand on a train than sit in the 2 empty seats opposite me. I have been told that lazy people use wheelchairs in airports (by the member of staff employed to push wheelchairs). None of my local busses are accessible for me and I can't use my local rail station. Very little of the London Underground is accessible, often the steep escalators make access impossible for those of us who use crutches for support.

Some new public buildings are thought to be providing adaptations for disabled people and meeting the guidelines for access. In reality some of the ramps provided are so steep and long that it is practically impossible for a wheelchair user to wheel themselves. A recent example of this is the new City Hall on London's South bank. When asked to comment a spokesperson stated that the guidelines had been met. Their website now advises disabled people to use the lifts and ask staff for help.

I have had to ask total strangers for help in using a ramp, and have sat outside shops in the rain waiting for a member of staff to notice me and produce a ramp. I now avoid shops that do not make access easy.

The RADAR scheme provides a key that can be used to access disabled toilet facilities but this has led to many being permanently

locked and if you have forgotten your key it is common to have to go to a designated spot and ask staff to unlock the facilities. A very important part of equality is to be given the same treatment as able-bodied people. To constantly have to ask for assistance is time consuming and can often be humiliating.

The Future.

As time passes access will improve and by 2020 rail services will be fully accessible. European legislation introduces some protection for disabled people travelling by air, part came into force in July 2007 and further regulations will be added by July 2008.

The DWP has an 'Access to Work' scheme that can provide funding for taxis, car adaptations and support workers/drivers when a disabled person starts work. Many organisations such as Leonard Cheshire through their 'Workability' scheme provide retraining in IT and support from experienced individuals to enable disabled people to return to work. All of these initiatives recognise the challenges and limitations of living with a disability and tailor the type and hours of work to suit the individual. Getting into or returning to work even if only for a few hours a week is beneficial in many ways for a person with a disability. These schemes do not pressure an individual towards a routine that is too much to cope with; rather they work with the individual and will only support them in a return to work if their circumstances are suitable. Many disabled people are unable to take advantage of these initiatives, but for those who can it is invaluable.

Technology is being used in innovative ways. A group of research students at IBM have developed a system to make public announcements (in stations, airports etc) available to people on a mobile phone. Called LAMA – or Location Aware Messaging for Accessibility - it enables a deaf user to receive text messages and blind people could have messages delivered in audio form.

Organisations for and of disabled people campaign for better access. The Equality and Human Rights Commission provides information and support and bodies such as the Disabled Persons Transport Advisory Committee work to ensure our needs are being met.

DLA makes a positive contribution towards equality and the Blue Badge scheme gives nationwide recognition to the needs of those with mobility problems.

Knowledge of disabilities and the ways our lives are affected by them are studied and the experiences of individuals are listened to. We are so much nearer to the ideal of equality and full access.

A Brief Overview of Occupational Therapy

Judith Holt

Our philosophy

“We believe that occupations (activities) describe who you are and how you feel about yourself. If you are unable to do things you want, or need to do, to live and enjoy your life, your general well-being may be affected. Occupation is important for everyone's life”.

There are over 26,000 qualified OT's in the UK. OT's undertake a degree level of training which includes both physical and mental health studies across all age groups.

All OT's generally work in the field of assessment, treatment and rehabilitation. You will find OT's working with physical disability, mental health, learning disability, children's services, rehabilitation units, and prisons, A&E departments, residential and day care facilities. The Local Authority or the N.H.S employs most OT's.

OT's use activity based interventions to achieve maximum independence and quality of life; e.g. advice on changing environment or ways of working and living with or without the use of specialised equipment.

OT's are primarily concerned with how clients function and maintain their quality of life in order to achieve their goals. They will use scales and scoring measures as well as practical assessments. They look at physical, psychological, social and environmental factors affecting the client e.g. – does the client have a significant disability? how they view it and what practical difficulties ensue. In other words “what stops me doing what I want to do?”

OT's skills would be utilised to find practical solutions, which could include specialised equipment, or psychological interventions according to need.

If requested OT's would provide written reports and assessments for hospitals, local authorities and other referrals indicating an assessment of the functional ability that could be expected of the client.

DM's may see OT reports written for the hospitals or the local authority outlining what level of disability the client has. Usually if an OT is involved there is some level of disability encountered.

MEETINGS WITH OUTSIDE ORGANISATIONS

The Board meets regularly with outside organisations. At these meetings Board members with relevant skills, expertise or interest have discussions with representatives of various groups.

The Board invites specific groups and also welcomes approaches from any group who feels it would benefit from meeting the Board. Recently we have met with representatives from the Bechet's Syndrome Society.

We use the News and Update as a means of directly informing DM's of changes that are new or brought to the Board's attention. This is in addition to the information already available in the Disability Handbook.

Updates to the Disability Handbook are being made via ICT where appropriate. Meeting with the Board gives access to representatives of outside organisations to inform us of issues needing clarification.

NEWS

In April we held a seminar for DMs at the Hotel Russell in London. Topics covered were Falls in older people, OT, Treatment of malignancies, and personal accounts of living with deafness and living with MS. We are planning a workshop/seminar in Cardiff for next year. Members have visited various DBC's and we think it important for all members to understand how DM's work and to experience their working environment.

Since the last issue our Information and Development Group has continued to monitor new developments and treatments for various conditions with the focus being on subsequent changes in the level of Care and Mobility needs.

Our website continues to include new publications by the Board and we are preparing this year's annual report. The conclusions of our study of Special Rules cases are also available on our site. We now have an internal search engine giving easy access to articles from all past issues of the News and Update as well as all Annual reports.

THE BOARD

Chair:

Mrs Anne Spaight MBE

Vice-Chair

Dr Ian McGill

Co-Ordinators:**Information & Development**

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& Ms Sarah Vines

Education

Mrs Clair Poole

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Mrs Judith Holt

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Mr Douglas Ross

Prof. David Scott

Mrs Christine Whitehead

THE REMIT

The Board has three main functions:

- To give advice to the Secretary of State on matters referred by him/her.
- To give advice to Department of Work and Pensions Medical Services doctors on cases referred for expert advice.
- To present an Annual Report on its activities over the year to the Secretary of State.

INVITATION TO DM'S

If you have any specific questions or general queries or suggestions please contact us via the Secretariat.

FOR YOUR INFORMATION

Please note - the articles contained in this news-sheet are written for the benefit of Decision Makers, to help them with their job.

The articles are **not to be quoted** in any decision or communication with members of the public or their representatives.

GETTING IN TOUCH

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