



**A celebration of the work of the
All Party Parliamentary Disability Group
and its Chair Rt Hon Lord Ashley of Stoke CH:**

four decades of parliamentary work for disabled
people's rights 1968-2008



About this booklet

This booklet highlights some of the achievements of the All Party Parliamentary Disability Group (APDG) and of its chairman, Rt Hon Lord Ashley of Stoke CH.

Jack Ashley is an outstanding parliamentarian and champion of disability and human rights. He founded the APDG in 1968 and has been its chairman for 40 years.

Throughout his time in Parliament Jack has been an effective and powerful advocate for the wronged and the disadvantaged; those experiencing discrimination and neglect.

At the end of 2007, RADAR decided to honour Jack for his Chairmanship of the group since its inception 40 years ago.

This booklet was commissioned and funded by the Royal Mail Group and written by Agnes Fletcher, who was researcher for the APDG from 1998 to 2001.



This 40th Anniversary booklet is sponsored by the Royal Mail Group



About Jack Ashley

Jack Ashley was born in 1922 to a poor couple in Widnes. He was only five when his father, a night watchman, died. Leaving school at 14 to work as a factory labourer, he became a shop steward six years later and was a local councillor by the age of 23.

He gained a scholarship to Oxford and another to Cambridge, where he displayed what he calls his “rebellious nature” by becoming the first president of the union to refuse to wear evening dress during debates.

1951 was an important year for Jack, who stood for Parliament for the first time but lost. He did get a job as a producer at the BBC, making mainly current affairs and documentary programmes. Far more importantly, that year he married Pauline Crispin, who he met at Cambridge and with whom he had three daughters.

Jack eventually became an MP, for Stoke-on-Trent in 1966. He was noticed immediately and many assumed he would become a minister. However in 1967, when he was 45, he became profoundly deaf as a result of a routine ear operation.

Jack feared, and many assumed, that he would have to abandon politics. Instead he learned to lip-read, helped by Pauline, and became the UK’s first completely deaf MP.

In the Chamber other MPs, including political opponents such as Ted Heath, helped him to take part in debates by turning to face him or giving him cues about his own speech. In this spirit of

cross-party cooperation he founded the All Party Disablement Group, as it was then known, in 1968.

However, political foes are just that. Jack was always outspoken and forceful. “That bloody Jack Ashley”, as he quickly became known, at first worried that opponents would be fearful of looking mean in attacking him. As his confidence returned and his combative nature was once more on display, such niceties fell away.

Jack soon became well-known outside Parliament as a powerful and passionate advocate for disability rights. His Civil Rights (Disabled Persons) Bill, presented in 1983, was the first piece of anti-discrimination legislation presented to the UK Parliament.

As a private member’s bill, without the support of the government, it fell. There were to be more than 10 further attempts before the government finally brought in its own legislation, in 1995.

Jack was made president of the Royal National Institute for Deaf People and in 1985 he and Pauline founded Deafness Research UK. In 1993 Jack’s hearing was partially restored by a cochlear implant a year after he ended 26 years as an MP and became a life peer, Baron Ashley of Stoke CH.

Jack has played a leading role in campaigns about thalidomide, which resulted in increased compensation for those affected and improvements in drug safety. He has campaigned on other compensation issues, such as vaccine damage to infants, the transmission of HIV to people with haemophilia and the arthritis drug Opren.

Jack and Pauline shared a strong belief in the need for justice for women and he became the first MP to raise the issue of domestic violence in Parliament. He also campaigned and secured changes to the law on rape.

Pauline died suddenly in 2003. Jack has described her extraordinary “clarity of mind and powers of concentration”, acknowledging her huge contribution to his parliamentary work. “We shared an anger against injustice which meant that we worked in harmony on subjects about which we both felt deeply.”¹ As Neil Kinnock has said: “When I see ‘Mr and Mrs Jack Ashley, Companion of Honour’, I know that Companion is in the plural.”²

Jack has continued to be a vigorous and effective champion of disabled people in the Lords, sponsoring a number of private member’s bills on anti-discrimination legislation and social care. The government’s Disability Discrimination Act 2005 mirrors his 2002 Disability Discrimination (Amendment) Bill. His current focus is the Disabled Persons (Independent Living) Bill.

Jack has initiated numerous debates on disability in the Lords and fought against aspects of government legislation that he felt were detrimental to disabled people, such as parts of the Welfare Reform and Pensions Bill of 1998-99.

Jack’s fierce opposition to injustice will always win him admirers. His humour, kindness and unfailing good cheer have also won him many battles and many friends.



About the All Party Parliamentary Disability Group

Indifference and neglect

In his autobiography, *Acts of Defiance*, Jack describes his generation's attitude to disabled people as "casual indifference slightly tinged with pity" – but "bordering on neglect".³

If we look back beyond the 1968-69 parliamentary session, when the All Party Disablement Group (APDG) as it was first known has its origins, the situation for most disabled people was grim.

Many were closely controlled in institutions or hidden and powerless within family homes. "In the whole field of social policy", wrote Margaret Beckett, Michael Meacher and Alf Morris in 1985, "there was no disadvantaged group so utterly neglected".⁴

Apart from legislation about those who became disabled in the armed services or through injury at work, there was very little state provision. The exceptions were the Blind Persons Act 1920, the increasingly ineffective Disabled Persons (Employment) Acts of 1944 and 1958 and the National Assistance Act of 1948, which promoted dependency not independence.

Nothing that aimed to help disabled people lead fulfilling lives had reached the statute books. Between 1959 and 1964 there was not a single debate on disability in the House of Commons.⁵ It was "government by neglect, reflecting public indifference".⁶

Disability as a human rights issue

The 1960s saw radical change in all parts of society, different relationships between individuals within the family and between social groups. In particular, people who had experienced disadvantage, discrimination and oppression began to assert a positive identity based on characteristics that had been seen as shameful in the past.

The disability rights movement had little real form or shape before 1965 and the question of rights, so hotly debated in the last 25 years, never arose in parliamentary or public debate.

However, from the 1966-67 parliamentary session onwards, the volume of references to disability and disabled people in Hansard increased. It was clear that there was increasing pressure for the improvement of services and rights.

Jack became an MP in 1966 and deaf shortly afterwards. With the support of his wife Pauline and others, he returned to Parliament. He met the campaigner Megan du Boisson. She had a great influence on him, stimulating his interest in disability.

Disability benefits then were pitifully inadequate. Megan had written a letter to the *Guardian* in 1965 calling for pensions for all disabled people, including women who did not work outside the home.

At a time when there was little political interest in disability, the effect of the letter was electric. Disabled people wrote to her expressing anger, frustration and despair. As Jack later wrote: "The failure to tackle disability was a failure of democracy. Millions of disabled people were being ignored and their views disregarded."⁷

The basic demand, which has echoed across the ensuing decades, was first articulated then: disabled people deserve a fair deal from the society of which they are part.

Megan established the Disability Income Group (DIG), which made contact with a number of sympathetic MPs and peers from each of the three main parties, supporting them to table repeated questions about provision for disabled people.

DIG also organised successful rallies in Trafalgar Square in 1967 and 1968, the second of which coincided with the United Nations Year of Human Rights. In the first issue of DIG's magazine

Progress, in 1968, the continued failure of government to address the needs of all disabled people was presented as a human rights issue – an historic moment.

Forty years later, this simple idea – of disability as a human rights issue – has finally achieved widespread currency.

The Chronically Sick and Disabled Persons Act 1970

One of the group's most active members from the start Alf Morris has, like Jack, focused on disability throughout his parliamentary career.

On becoming an MP, Alf's understanding through family experience of the problems faced by disabled people was heightened by seeing the plight of his constituents. People who were born disabled trapped in long-stay hospitals with little or nothing to do; older people becoming disabled and struggling to preserve their dignity against all odds; people of all ages living in dire poverty and isolation, warehoused in restrictive institutions or imprisoned in the back rooms of unsuitable housing.

There was often a common thread: they didn't want to be institutionalised against their will. They didn't want the only alternative to be forcing their families to give up work and devote their own lives to providing support. They wanted to live an ordinary family life and to have choices.

The APDG's first major challenge was to support Alf's Chronically Sick and Disabled Persons Bill, his attempt to make those aspirations a reality.

By 1969, there was a rising tide of awareness of the neglect of disabled people. Alf later wrote: "There were more and more people outside, as well as within the two Houses of Parliament, who were now determined to change and humanise the law. Metaphorically speaking, disabled people were on the march and we were marching with them." ⁸

When Alf was successful in the private member's ballot, he decided to attempt a highly ambitious bill to give practical help to disabled people.

There was strong support from all parties to ensure that this complex bill was enacted before the general election of June 1970. Members of the group took part in briefing sessions, helping to agree a cross-party backbench line to put to ministers and officials.

There was a marked lack of enthusiasm for the bill from the Secretary of State, so much so that when Alf went to discuss it with him he was told to drop disability rights in favour of organ transplants.

However, faced with cross-party support, the government did not oppose the bill outright. The landmark act of 1970, the first to acknowledge disabled people as ordinary citizens, was passed. It set the tenor of future attempts to secure a better life for disabled people through primary legislation.

The process of securing the legislation helped to galvanise and strengthen the APDG. The group has continued to surprise governments of both main parties with the energy, commitment and organisation of its members, its constructive contact with the grassroots and its flair for publicity.

Disability as a political issue

From the 1970s, organisations of disabled people began to spring up around the country. In their thousands, disabled people and their families and friends, with growing support from inside Parliament, began to transform political and public opinion.

The change was from complacent charitable indifference to acceptance that disabled people did not have – but were entitled to – independent and dignified lives as full members of their families and society. No longer were they to be seen as excluded half-humans reliant on handouts.

The older disability charities began to tackle disability as a political issue and to launch campaigns for change, where the emphasis before had been on charitable provision that effectively maintained the status quo.

Newer groups of disabled people looked beyond benefits issues to discrimination. The Union for the Physically Impaired Against Segregation (UPIAS), founded by academics and activists such as Paul Hunt, Vic Finkelstein and Mike Oliver, defined the social model of disability.

The British Council of Organisations of Disabled People (now the UK Disabled People's Council), an umbrella group formed in 1981, the International Year of Disabled People, sought to provide a democratic voice for thousands of disabled people.

Throughout the APDG's existence, pressure inside and outside Parliament for legislation to tackle discrimination against disabled people has grown. Not only backbenchers but also party leaders began to take note as the years passed. A landmark was reached when, in 1974, the Prime Minister Harold Wilson created a new post. Alf Morris became the world's first minister for disabled people.

Although attached to the Department for Health he liaised with other departments on issues affecting disabled people. As the progress of the Chronically Sick and Disabled Persons Bill had shown, there are few areas of policy that do not affect disabled people's lives.

During Alf's tenure the foundation was laid for today's basic disability benefits, attendance and mobility allowances (now combined as disability living allowance for the under 65s); invalidity benefit (now incapacity benefit) and invalid care allowance (carer's allowance).

The APDG was directly involved in the legislation that brought about these changes. As members of the group know from their contact with disabled people, the sharp end of disability is often poverty not pain. Disability means extra costs and missed opportunities yet it can reduce or eliminate the ability to pay for them.

The group's many other campaigns include those for a fair settlement for those disabled by thalidomide, access to justice, housing, transport, education, employment, leisure and participation in the political process itself.

The fight for civil rights

The report of the Committee on Restrictions Against Disabled Persons (CORAD), chaired by Sir Peter Large, in 1979 found that discrimination was just as extensive in relation to disability as to race or sex. It quoted many absurd examples, such as the draughtsman whose job offer was withdrawn when he said he had a prosthetic leg and the holiday camp that refused to allow disabled campers in the summer, claiming that this was because the area was hilly – while offering to accept them in the winter.

Unfortunately, no government action was taken on the recommendations for new legislation. So in 1983, Jack drew up the first private member's Civil Rights (Disabled Persons) Bill to outlaw discrimination on grounds of disability. It provided for a commission, with powers to conciliate and to take legal action when necessary.

Donald Stewart, leader of the Scottish National Party, having been successful in the private member's ballot, took it up. The bill failed to get its second reading by 23 votes.

In 1986, Tom Clarke was successful in the ballot and also chose disability. His bill began as a modest measure to improve disabled people's rights but with help from disability organisations, local

authorities and the APDG he was able to construct a radically reforming bill.

Its proposals included the right to appoint a representative to act on a disabled person's behalf; the right to a voice in the assessment of support needs; and improvements in coordination of public services.

Tom saw his bill enacted in July 1986 as the Disabled Persons (Representation, Consultation and Services) Act, although many of its most important clauses were not implemented. When it became obvious that this was the case, a mass lobby was proposed. House officials said that Westminster Hall could not be used; the police said no parking facilities were available; the media showed no interest.

The APDG wrote to all MPs informing them of the lobby and inviting them to attend. After much effort, everything fell into place. Westminster Hall was made available; the police allowed special parking; even National Car Parks gave free spaces close the Commons.

The day itself, 8 April 1987, was a triumph. Westminster Hall and Central Lobby were packed. Over 200 MPs came, including the leaders of the parties. The government eventually implemented more parts of the Disabled Persons (Representation, Consultation and Services) Act, although some of it remains unimplemented to this day.

The members

The group was from the very start genuinely cross-party. Jack approached John Astor, Conservative MP for Newbury, to be Secretary when he formed the APDG. John supported disability issues and rarely objected to the group's activities even when, as in the early 1970s, they were critical of the then Conservative government.

When John left the House in 1974, he was replaced as Secretary by John Hannam (now Sir John), another Conservative. Despite being a member of the 1922 Committee, the Conservatives' powerful backbench group, John maintained the strong cross-party stance and this continues to this day, with Conservatives such as Tim Boswell and John Hayes and Liberal Democrats such as Paul Burstow taking officer roles.

Many of those who have been active over the years are those with personal interest in disability, such as Rt Hon Dafydd Wigley, now a Member of the Welsh Assembly, who was a Vice-Chair.

Roger Berry, entering Parliament in 1992 and succeeding the MP who talked out one of the Civil Rights (Disabled Persons) Bills, is the current Secretary and has campaigned very effectively on disability throughout his time in Parliament. Other active Commons members over the years include Peter Thurnham, Tom Clarke, Bob Wareing, Peter Bottomley, Tom Levitt, the Rev. Martyn Smith and Theresa May.

There has always been strong representation from the Lords. Some members – Sue Masham, Davina Darcy de Knayth, Felicity Lane Fox and Martin Ingleby – were known early on as “the wheelchair brigade”.

A formidable group, together with Alf, now Lord, Morris, Denis Carter, Beatrice Kinloss and Barbara Loudoun, they ambushed governments on many occasions, using the gamut of parliamentary tactics: from parliamentary questions to the well-timed offer of a drink to a new member during an important vote.

Roger Swinfen, Brian Rix and Gordon Campbell have been other long-standing advocates of disability rights, alongside newer Lords members such as Rosalie Wilkins and Jane Campbell.

Rights Now!

The early 1990s saw an increasingly coordinated disability rights movement outside Parliament, further private member's bills inside Parliament, and the development of the *Rights Now!* campaign, chaired first by Stephen Bradshaw and then by Rachel Hurst.

Rights Now! grew out of a campaign group started by the big disability charities, Voluntary Organisations for Anti-Discrimination Legislation. It was a coalition of disability organisations, with support from unions and human rights bodies, for civil rights for disabled people.

The campaign had strong links with parliamentarians. Its work was coordinated by the APDG's researcher at the time, Victoria Scott, and by a volunteer, Adam Thomas.

Disability campaigners in Parliament have often found that when disabled people are mentioned, MPs and peers tend to nod approvingly. They are well disposed and anxious to express their support – but there has not always been the venom in debate characterising other political issues. Because of this, disability used to be seen as a political sideshow, of little public or media interest.

That changed in 1994, when the Civil Rights (Disabled Persons) Bill was once again tabled as a private member's bill by Roger Berry. By now, it was a far-reaching and detailed piece of legislation, drawn up with disabled lawyers Caroline Gooding and David Ruebain.

Despite support from a majority in both Commons and Lords, the government of the day was set against it and the bill met its end of the floor of the Commons during its Final Reading.

There were strong words inside Parliament and outcry outside it, in part because of the parliamentary tactics necessary to stop a bill with majority support - with direct action by disabled people.

The media nationally and internationally took a keen interest in the issue, fuelled by the fact that one of the chief spokespeople for the bill, Victoria Scott, was the daughter of the minister for disabled people, Nicholas Scott.

Nick was a strong supporter of disability rights, with experience of disability within his immediate family. Nevertheless, as the relevant government minister, it was his job to see that the government's will was done.

Despite wrecking the bill, the Conservative government brought forward its own Disability Discrimination Bill the following year – the first government-sponsored bill of its kind. The argument about the need for legislation was over. What remained was what form that legislation should take. It is an argument that continues today.

Comprehensive and enforceable civil rights for disabled people

In the years since the passage of the original Disability Discrimination Act 1995, judged by Lord Lester to have as many holes as a particularly leaky colander, there have been many improvements.

The exemption from the act's duties of employers with fewer than 20 employees has gone. The definition of who has rights has widened, to include those with cancer, multiple sclerosis and HIV from the point of diagnosis and many more people with mental health conditions.

In 2001, absence of rights and duties in education was corrected via the Special Educational Needs and Disability Act 2001.

One of the largest flaws in the original legislation was the absence of an enforcement body – something that Jack had seen fit to put in his very first private member's bill back in 1983.

The Disability Rights Commission Act 1999 made provision for a Disability Rights Commission, which opened the following year. Jack led moves within Parliament to strengthen the commission's powers and to provide that either the chair or vice-chair must be disabled.

Jack worked closely with the commission from 2000 until its closure in 2007. He presented a private member's Disability Discrimination (Amendment) Bill in 2002 to strengthen the DDA, which was eventually reflected in the government's own Disability Discrimination Act 2005.

This last major change to the original legislation removed the exemption of transport and introduced a positive duty on the public sector to promote equality. The disability equality duty as this is known at last shifted responsibility for tackling discrimination from disabled people onto public sector organisations, which have to dismantle institutional barriers to disabled people's equality.

Tackling poverty, promoting choice and voice

With anti-discrimination legislation appearing firmly on the statute book, Jack looked at other ways of improving the lives of disabled people and their families.

He led the campaign to ensure that disabled people were no worse off following changes to incapacity benefit brought in by the Welfare Reform and Pensions Act 1999 and has taken an increasing interest in social care and related public policy issues.

The APDG has realised for many years that formal equality is meaningless without the support to make choices about daily living.

When Paul Hunt and others with very significant physical impairments and personal support needs left Lee Court residential home in the late 1960s to make a life for themselves and others

“on the outside”, they were living the new philosophy of ‘independent living’ – life on one’s own terms with the full range of choices enjoyed by others.

In the past few years, securing rights in relation to housing, social care and advocacy for all those who need such support has provided a new focus for Jack’s energy and skills.

His independent living bills, supported by Caroline Ellis at the Disability Rights Commission and others, have brought into Parliament discussion of fundamental questions about what it means to be human; what a decent life means in Britain; how we can provide effective social care today and meet the challenges of demographic change.

The future

Marking 40 years of the APDG’s life serves as an important reminder that such rights as disabled people have now have been hard won. They are the fruit of many years of dedicated campaigning, inside and outside of Parliament, and must be safeguarded against erosion and evasion by those who might wish to dilute or deny them.

Disabled people still do not enjoy full social inclusion and equal citizenship. However, the group has shown how powerful Parliament, disabled people, the media and public opinion can be when combined to effect change. To start with, the group had just a handful of members. Today, it is one of the largest in Parliament.

As Jack explains in *Acts of Defiance*: “The world of disability is like a turbulent sea. New thoughts, ideas and beliefs are constantly rising to the surface, being tested and then carried on either an outward or inward tide. The group is the channel through which the new and sustainable ideas are funnelled into Parliament and legislation.”⁹

The APDG has conveyed new thinking to Parliament and government and seen it enacted in legislation. It has fought for new rights and also sought to prevent legislation that could leave some disabled people worse off.

Jack has described the work of the group as the task of Sisyphus,¹⁰ condemned in the Underworld to push a stone up a hill – only to watch it roll down and to begin again. No sooner is one disability wrong addressed than another takes its place.

While the beauty of Westminster has perhaps more in common with Paradise than Hades, over the years every aspect of disability has been addressed here, from antenatal care for disabled newborns, to poverty, the built environment, communication aids and end of life care.

The task of Sisyphus continues in the need to update equality legislation to make it fit for the 21st century. The Disability Rights Commission has gone and the APDG must help to ensure that the Equality and Human Rights Commission can effectively enforce and promote disability equality.

The task of Sisyphus is evident also in the erosion of rights to support with personal care inside the home.

While it may be the task of Sisyphus, the work of the APDG is supported with vigour by all those involved. It is a noble task, shared by disabled people and their friends and families outside Parliament. The more hands on the metaphorical stone, pushing it up the hill, the lighter the burden carried by each person. The sooner choice and dignity are assured for those affected by disability or long-term ill health, the better for us all.

Acknowledgements

All who have worked with and for the group acknowledge the help and support of the staff at the Palace of Westminster.

The APDG has benefited throughout most of its existence from support from RADAR in a form of a researcher provided to support its work.

Over the years, Phyllis Foreman, Peter Mitchell, Raewyn Stone, Diana Sutton, Fidelity Simpson, Susan Eastoe, Jane Oberman, Victoria Scott, Agnes Fletcher, Juliet Tunney, Haqeeq Bostan, Bethan Colins, Ruba Sivagnanam and Beth Capper have provided research and administration services.

Endnotes

1 *Acts of Defiance* (1992) by Jack Ashley, published by Penguin.

2 *ibid*

3 *ibid*

4 *As of Right* (1985) by Margaret Beckett, Michael Meacher and Alf Morris

5 *Be It Enacted: 25 Years of the Chronically Sick and Disabled Persons Act 1970* (1995) by Ann Darnbrough and Derek Kinrade, published by RADAR

6 Ashley, *op. cit.*

7 *ibid*

8 *No Feet to Drag* (1972) by Arthur Butler and Alf Morris, published by Sidg. & J

9 Ashley *op.cit.*

10 *ibid*



This 40th Anniversary booklet is sponsored by the Royal Mail Group



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