



All Party Parliamentary Group on Autism

Minutes of AGM and Meeting on the Independent Living Bill 12th July 2006, Committee Room 14, House of Commons

In attendance

Lord Ashley
Liz Blackman MP
Bob Blizzard MP
Lord Clement-Jones
Janet Dean MP
Helen Southworth MP
Betty Williams MP
Stefano Ghirardi, representing Baroness Morris of Bolton

Apologies

Lord Astor
Tim Boswell MP
Peter Bottomley MP
David Drew MP
Sandra Gidley MP
Paul Holmes MP
Tim Loughton MP
Rudi Vis MP
Lynda Waltho MP
Hywel Williams MP

AGM

- Liz Blackman MP said she is privileged to have been chair of the APPGA, but must stand down due to her promotion to Government Whip.
- Janet Dean MP was proposed as the new chair by Helen Southworth MP. Agreed.
- Bob Blizzard MP was proposed as a new vice-chair by Betty Williams MP. Agreed.
- Janet Dean MP noted that all current officers stated they would stand for re-election and were elected unopposed. The officers' positions were confirmed as Paul Holmes MP (Treasurer), Tim Loughton MP (Vice-Chair), Lord Clement-Jones (Vice-Chair) and Lord Astor (Secretary).

Meeting on the Independent Living Bill

Background: on 8 June 2006 Lord Ashley presented his Disabled Persons (Independent Living) Bill to the House of Lords. It is a Private Members Bill that, if passed, would introduce a number of new rights for people with a disability, as well as duties upon local and central government. The Bill follows extensive work on independent living with the Disability Rights Commission. Its second reading took place shortly after the meeting, on Friday 14th July.



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Speaker – Lord Ashley

Lord Ashley discussed the need for a transformation in the attitude of government towards disabled people, who each have a right to independent living. Existing rights and entitlements have been sporadic and patchy. Given the PM's Life Chances report, and David Cameron's interest in disability, Lord Ashley hopes that the parties will support the Bill.

The Independent Living Bill would impose a duty on government to compile a central register of disabled people and their needs, and to produce and implement a strategy for independent living. The bill would create a similar duty on local authorities and Health Service bodies. A disabled person's assessment would be self-led, and take into account that person's own view of their requirements.

In terms of how it would help people with an ASD, Lord Ashley mentioned:

- Alongside the existing Disability Equality Duty, the Bill would work to improve the design and delivery of services.
- It should work to disregard negative public opinions about disability – and he said these exist moreso about autism than about other disabilities.
- A new definition of disability used fully incorporates ASD.
- Awareness of disability and accessibility.
- Pooling of resources between bodies, so that people would only have to negotiate with one body and not several.
- People would be notified upfront their allocation of resources and they could spend it as they pleased.
- Practical support for disabled people and their families, in any or all parts of life, including shopping, employment, cooking and looking after children.

Lord Ashley added that the DRC had been an enormous help and had made a major contribution to the Bill.

Speaker – Graham Nickson, Disability Rights Commission

The DRC fully endorses Lord Ashley's Bill.

Graham Nickson emphasised the importance of advocacy and communication support in accessing housing, education, employment, leisure and health services. Reduced access to advocacy is a major barrier to those with an ASD. The Independent Living Bill would guarantee advocacy services to those on the spectrum.

The Bill would ensure that no disabled person would be forced to live in residential care. They could choose to do so, but they would not be forced to do so, just because it was financially convenient for a local authority.

Local authorities would be required to maintain a disability housing register, and homes would be built to the lifetime home standard.

EDM 2399, in support of the Independent Living Bill, has already been signed by 85 MPs. He asked MPs present to sign it.



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Questions

Bob Blizzard MP: Is there anything in the bill to ensure disabled people have access to adequate holiday accommodation?

- Graham stated that while there is no specific clause in the bill relating to holiday accommodation, public attitudes may be changed via the bill and in turn this may engender a change in accommodation quality. He also noted the need for the tourism industry to recognise the spending power of disabled people.
- Lord Ashley stated that in addition, discrimination of this kind (inaccessible accommodation etc.) is illegal under the Disability Discrimination Act and should be reported.

Louisa Stevens, English Community Care Association, said the Bill's effect on care homes had received negative coverage in the press, but the Bill itself talks about choice, which is right. There needs to be more than enough care homes and domiciliary housing, though, in order to enable choice. There is a danger of 'independent' being interpreted as having to live on your own. Certain people in care homes are more independent because of the care they receive, it depends on the individual's needs and requirements. How will the Bill account for this?

- Graham emphasised that the focus of the Bill is on more readily available accessible housing, so that the relative merits of each option can be satisfactorily judged. Access to choice would be available, rather than a 'care homes or nothing' system, as exists in some areas currently.

David Shamash asked firstly, whether people with Asperger's Syndrome would be recognised in the Bill as well as those with autism. Secondly, a postcode lottery of provision currently exists. Services like Freedom Passes and Social Workers are allocated differently from one local authority to another, meaning people can lose their provision if they move. Will the Bill address this?

- Graham noted that firstly, Asperger's is recognised within the Bill as a disability; and secondly, the Bill encompasses the idea of 'portable support', meaning that a package of support should follow you from one local authority to the next.

An observer said any package of support is ultimately governed by each local authority budget. Need has to drive in this case; will this be looked at? Also, in terms of advocacy, there is already a lack of well trained advocates. She asked whether Lord Ashley considered that a blanket approach to advocacy may be unnecessary. Thirdly, when fighting the system she had been ignored because a single person in the local authority had not been responsible.

- Lord Ashley stated that specific provision would be available in each local authority for those who need it. As for advocacy, access to it is a crucial part of the Bill, and inherent in the new notion of self-led assessment. He added that local authorities avoiding accountability because a single person was not responsible sounded fishy, and that the local authority must take responsibility.
- Graham added that under the Bill, people would be given access to advocacy support if they need it. Whether they use the advocacy services available to them would be entirely up to the individual in each case.



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Julian Wiseman asked whether it is not humiliating for people to be placed in care homes when they don't want to be there.

- Lord Ashley said no, it was not humiliating, but the Bill was about stopping involuntary institutionalisation, which is indeed unacceptable. However, some people want to be in care homes, when given the choice. The Bill would also change the Human Rights Act so it applies to private and voluntary sector care homes.

An observer said that all local authorities have a threshold of care. Even if there were a list of disabled people, authorities would still place a threshold and only provide services to those with needs above the threshold. How would the Bill solve that?

- Lord Ashley stated that if there is a refusal to assess, or to provide support, then the local authority would have to explain why. The bill would put increased pressure on local authorities to be accountable.

The observer replied that the current situation left people with an ASD to fall into gaps between services, their needs not being met (or even assessed in many cases) by any local authority teams.

- Graham said that the Bill intends to address the barriers for people with an ASD and attempt to tackle them. Minimum outcomes would be set centrally, against which local authorities could measure their achievement.

Lord Clement-Jones: There are huge numbers of adults with autism who are hidden from view. Now that there are many more children diagnosed, we are looking at a tidal wave of problems once children leave school; the key thing to develop is independent living. There is a need for statutory change, or it will not happen.

David Shamash asked which local authority department will look out for people with ASD?

- Graham stated that it is time for local authorities to acknowledge that delivering support to people with ASD is part of their remit, and should not require a separate department.

Rhya Homewood: In practice this does not work; local authorities want people to fit into a box so they can allocate funding.

- Graham emphasised the need to move away from this kind of labeling, and that this could be achieved through the various reforms set out in Lord Ashley's Bill.