

Disability Rights Commission

Learning lessons:
The Independent
Living Bill –
building strategic
alliances

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Executive summary

The Learning Narratives project contributes to the broad legacy strategy of the Disability Rights Commission. It considers what the DRC has learnt through its various activities since 2000 and focuses on specific activities or overarching themes where the DRC has had direct involvement.

Each narrative responds to questions such as ‘why did we, the DRC, try to do what we did?’, ‘what worked?’ and ‘what didn’t work and why?’ and draws on a range of data sources, not least of which is the experience and expertise of DRC staff, both past and present.

This narrative considers the work undertaken by the DRC on its Independent Living Bill (IL Bill). It looks at what the purpose of the Bill was, how this allowed the DRC to influence key stakeholders, and how it helped the DRC build alliances with new and different groups. It also considers some of the issues that forming such alliances created.

The Independent Living Bill: key lessons

Using Bills

- A Bill can be used as a Trojan horse; it is a mechanism to highlight a range of issues and promote a deeper understanding of a subject.
- In developing a Bill, it should draw on existing research and policy, and be very much evidence led.
- An organisation should be proactive in ensuring the evidence within the Bill is used to influence other agendas aligned to the issue in question. The Bill then has other

benefits insofar as shaping other policy agendas in a broader context.

- A Bill can be an extremely powerful tool in garnering cross-party support, and building wider strategic alliances.
- A Bill should not include 'everything but the kitchen sink' but rather should incorporate a package of issues which will maximise its chances of success. In other words, a pragmatic approach to producing a Bill is needed.
- An organisation will need to consider the timing for the Bill, preferably piggy-backing on external events to maximise its impact.
- Nevertheless, it is impossible to control the external environment and those activities / events which will impact on the Bill. Therefore, the Bill team will need to be both proactive and flexible in determining timescales etc.
- Choosing who sponsors the Bill is a vital aspect of the Bill's likely progress and influence.
- To maximise its impact, a Bill needs to be accompanied by an influencing media strategy. A Bill on its own will only have a limited reach.
- Any Bill needs to be fully costed from the outset. On the whole, it is always better to work with the relevant government department on this from the outset as it provides a level of credibility for the proposals put forward.

Building alliances

- The DRC found it was important to acknowledge the wider interests of delivering Independent Living, and to

bring on board other social groupings to take ownership of the Bill, alongside traditional disability organisations.

- In producing a Bill it will be important to map out with strategic partners the different mutual interests, and how best these can be promoted.
- In terms of strategic alliances, it is important to acknowledge that organisations will have different priorities and motivations for being involved. The key is to recognise this and to ensure understanding across the alliance and the building of mutual respect.
- Alongside developing broad-ranging strategic alliances, it is important to communicate to all groups the reason behind the decisions taken, as it is important not to marginalise more traditional partners.
- An organisation will need to weigh up the merits of the strategic alliance in determining the level of formality which should be applied. There is no one model and factors will vary over time, so a flexible approach will always be needed. A risk strategy should also inform the approach.
- Building strategic alliances might mean working alongside organisations that traditionally have not shared your view on particular issues, in order to deepen the strength of the coalition.
- During the lobbying process the DRC 'managed' the amendment process. Some organisations felt this was an efficient and effective way forward, while others felt the DRC held too much control. If a 'managed' process is chosen, it will be important to set out transparent amendment criteria against which each suggestion can be assessed.

Introduction

This narrative considers the work undertaken by the DRC on its Independent Living Bill (IL Bill). After providing a broad background to the Bill, the narrative will look at what the purpose of the Bill was, how this has allowed the DRC to influence key stakeholders, and how it helped the DRC build alliances with new and different groups. The three key alliances are then discussed, as well as some of the issues that forming such alliances created.

Context

What is Independent living?

The DRC defines Independent Living as follows:

All disabled people having the same choice, control and freedom as any citizen – at home, at work and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves' but it does mean that any practical assistance people receive should be based on their own choices and aspirations.

Background to the Bill

In 2004, the DRC took the decision to prioritise the campaign for Independent Living for disabled people. The idea of launching a Bill was not initially proposed – instead, a broad influencing strategy was developed with the intention of improving access to support services for all disabled people. As the campaign progressed, however, the severe lack of rights of disabled people uncovered in the area of Independent Living prompted a Private Members' Bill and a move toward the campaign for new legislation began.

What did the Independent Living Bill cover?

The IL Bill was based around a new legislative framework for Independent Living rooted in the principles of freedom, dignity, choice and control. It is geared towards greatly expanding the active participation of disabled people and those who would otherwise provide unpaid support to them in social and economic life. Specific proposals within the IL Bill included a single assessment for social care, housing support, employment support and health services funding

and clearer rights to essential support to increase independence for disabled children and adults.

Bills themselves are about more than just the legislation they seek to change. In the 1980s (i.e. before the Disability Discrimination Act and the Disability Rights Commission) a series of Private Members Bills were used in an attempt to establish anti-discrimination legislation on the statute. In particular, Dr. Berry's Civil Rights (Disabled Persons) Bill proposed comprehensive anti-discrimination legislation which, despite a high level of cross party support, was ultimately amended out of existence. Despite being defeated, the key effect of the Disabled Persons Bill, and all previous attempts was a heightened awareness amongst MPs, the media and the general public of the issues faced by disabled people and the lack of a legal framework to tackle this. As such, these Bills ultimately helped lead the government of the day to establish its own legislation in the form of the Disability Discrimination Act (DDA) 1995.

The purpose of the IL Bill is the same. The Bill itself was not expected to be voted wholesale onto the statute book, but rather to influence the cross-party Independent Living Review Panel and to get people thinking about 'Independent Living' as a rights issue. It also made the DRC a major player within the field of campaigning around independent living and social care.

Developing the IL Bill

The initial drafting of the IL Bill proved relatively straightforward, as there was a wealth of existing research and policy on the issue. The internal DRC Independent Living working group had developed policy positions over previous campaigns and so by the time a formal IL Bill was required there was a clear idea of what it should cover.

Prior to the Bill being developed, though, Independent Living had – for the most part – remained something of a ‘philosophy’ rather than a set of defined priorities at the DRC. Writing the Bill meant that Independent Living had to be clearly defined and so this process therefore helped the DRC crystallise the meaning of independent living. As such, one of the Bill’s major achievements was to outline practical steps that could be taken to achieve an increase in Independent Living for disabled people. The DRC and other advocates of Independent Living recognised the need for a system that gives people greater control over their social care, and it is widely believed that these ‘theoretical underpinnings’ of the Bill have won the day, even if the Bill itself is not passed.

Consultation

Quite early on in the initial drafting period, a ‘pre-consultation’ email was sent to organisations to establish possible content for inclusion in the Bill and to gather information. At this stage in the Bill’s development there was no kind of alliance between the DRC and other organisations.

After the initial drafting was complete, the Bill was discussed more fully with relevant stakeholders – discussion which led to amendment to the Bill. Organisations, and in particular carers’ organisations, lobbied the DRC to amend and add specific propositions to the Bill. These early drafts after stakeholder consultation had a very wide and probably too unrealistic ambitions which risked the credibility of the overall package of proposals. The DRC therefore needed to further revise many of these amendments to avoid skewing the focus of the Bill and diluting their message. Thus, the consultation process, and especially that which took place with MPs, demonstrated clearly to the DRC that the wholesale inclusion of DRC policy would not be the most effective message to send the government: if the demands made were too extensive, the Bill would have little chance of achieving its

goals. Consultation had added subtlety and pragmatism to the Bill

Launch of the IL Bill

The timing of the launch of the IL Bill was tied closely to the release of the Prime Minister's Strategy Unit's Report 'Improving the life chances of disabled people', which was published in January 2005. This report, which had been developed with the DRC, stated that a focus on disabled people was part of the government's vision for the next 25 years and that Independent Living was a central part of that strategy.

The publication of this report therefore provided a good context for the Bill and the Independent Living Bill was drafted and launched in June 2006. At the same time, a cross-party, Independent Living review panel was also set up, to try and turn the report's recommendations into policy and, ultimately, legislation.

Making amendments to the Bill

During the readings and the committee stage of the Bill, amendments are officially debated in the House and anyone can lobby for an MP to make an amendment. This lobbying process was managed by the DRC, inviting all organisations who wanted to lobby to do this through the DRC, allowing it to marshall amendment propositions. Within the alliance that had formed around the IL Bill, there was a mixed reaction to the DRC's role: some felt that the brokering and managing role was inappropriate for the DRC to perform, whilst others were happy that the DRC took this lead and thought it was done well. Irrespective of the views of the alliance, the process was made transparent through a set of amendment criteria against which each proposition was assessed. Such criteria were felt to be a successful way of managing the

amendment process as it made it fairer and reduced the potential for other organisations to claim that the DRC was seeking to overly-control the consultation process.

A muted government response

Unfortunately, a number of key issues conspired against the DRC and meant that the government's response to its Independent Living Bill in 2006 was relatively low key.

The issues were difficult to control. First, the DRC knew that in 18 months it would no longer be in existence and would have been replaced by the Commission for Equality and Human Rights. Second, the publication of the Independent Living review panel's final report was not due for some time, meaning that waiting for the report would have left insufficient time to draft the Bill before the end of the DRC.

As a result, it was decided that a 'wait and see' approach was a great risk to the independent living agenda, and the DRC decided to progress with the Bill. The failure to wait for this report however led to the government's muted response to the Bill. It is suspected that the government felt that the DRC should have waited for the review because once the Bill was published a response would be forced.

Bills and their relationship to policy

Whilst the end result of the majority of Bills – and especially Private Members Bills – is not legislation, their impact can still be far reaching. In the case of the IL Bill, the Independent Living review panel used the Bill as a key reference point for their work throughout. Despite the fact the review panel is likely to pare down the IL Bill's recommendations to a more 'realistic' set of options to present to the Government, these options will still have been shaped by the DRC's Bill – a key achievement.

Learning lessons: The Independent Living Bill – building strategic alliances

Indeed, a key piece of learning from the IL Bill is to see Bills in general as a potential tool for influencing and lobbying ministers. This therefore broadens the scope of any Bill's more obvious purpose to seek change in existing legislation. However, a Bill cannot influence and lobby on its own – it needs to be accompanied by an influencing media strategy to bring issues like Independent Living 'out of the ghetto' and into the more mainstream areas of media reporting and political consciousness. For the DRC, this meant positioning the rights to Independent Living for disabled people as a central part of a wider debate around social care – an issue that impacts not only disabled people but other social groupings.

To do this, the DRC formed strategic alliances with relevant organisations, formed around the broad aims of the Independent Living Bill, and helped to identify and map the mutual interests of these different social groups.

Building strategic alliances

Strategic alliances were the key to the development and impact of the Independent Living Bill. The narrative now considers the three key types of alliances that were formed around the IL Bill and some of the issues that forming such an alliance created.

Forming the alliance: Lord Jack Ashley

Choosing who backs a Bill is a vital aspect of a Bill's progress.

After an open meeting at Portcullis House with MPs who had previously worked with the DRC or had expressed an interest in Independent Living issues, the choice was made easily after Jack Ashley put his name forward. Although brief discussions did take place around the impression that choosing a veteran disability campaigner might have on the Bill – the 'usual suspect' argument – it was ultimately felt that having a backer who could demonstrate a strong commitment to disability issues overrode any other concerns.

It was necessary, however, to demonstrate a wider appeal in order for the Bill to be influential in Parliament.

Forming the alliance: other organisations

The wider appeal of the Bill was secured through its development by and support from an informal alliance of disabled peoples' organisations which became active after the initial stages of the Bill's development. The alliance formation was not planned – rather, it grew organically as

the shared interests became clearer through both informal contact and formal meetings between interested organisations.

It is more appropriate to consider the alliance in terms of an informal network of organisations that recognised their shared interests in the broad aims of the Bill than a fully formed group. The development of the strategic alliance of organisations with an interest in Independent Living, therefore, was intended to be an ongoing and enduring process rather than solely for the purposes of campaigning for the Bill. As such, it is hoped the alliance will continue beyond the end of the DRC.

There are, however, some divisions within the network between the different organisations and their priority focus. On the one hand there are the disability rights organisations who regard the Bill as the completion of the disability rights journey. Their primary goal is focused entirely on the right to Independent Living being achieved.

On the other hand there are the organisations that maintain a wider focus, for example the Equal Opportunities Commission, Carers UK and organisations representing older people. For these organisations, it is not so much the content but the possibilities of legislative implications for their constituencies that commits them to the Bill.

Key members of the alliance

Engaging the carer lobby was key to the alliance. In the past, the relationship between the disability lobby and the carer lobby had not always been collaborative. As such, during the initial drafting of the IL Bill, the DRC was inclined to see the carer lobby as a potential interested stakeholder but one that could possibly pose a potential threat to the IL Bill.

But having identified the importance of carers in the aims of Independent Living, it became important to map the shared interests and goals between the two lobbies, and therefore secure a broad alliance that would demonstrate to the government that Independent Living was not an issue confined to one particular group within society, but an 'everybody issue'. Additionally, getting the carers' lobby on side has had an added benefit because of its influence in the field of social care. Overall, a combined effort between the carer and disability lobbies was felt to increase the chances of securing government investment. Such an alliance was bound to raise some eyebrows amongst the more radical disability groups, so a strategy of engaging and explaining the reasoning for this move was undertaken at the same time.

The Equal Opportunities Commission (EOC) were also involved in the alliance, because they viewed Independent Living as a gender equality issue due to the fact that the vast majority of carers are women. This involvement not only allowed the DRC to progress its Independent Living aims, but also provided the DRC with an opportunity to make links in preparation for the CEHR. More generally, Independent living has a wealth of intersections with, and undercuts, many of the equality strands. As such it provides a timely platform upon which to ensure that the issue is included in the CEHR agenda.

Forming the alliance

The practical steps of forming the alliance were important: under Chatham House rules, a meeting was convened between all the key players, at which all concerns about working together were laid bare. The meeting allowed the process of working on the Bill to get underway without formally announcing the formation of an alliance and, since

the formation of a coalition was never ultimately formalised, no terms of reference were developed.

Concerns in alliance working

There had been concerns expressed about the informal nature of the alliance, but a weighing of the risks meant that the flexibility afforded by an approach allowed the alliance to respond more quickly and act with a sense of urgency when required. With terms of reference for the alliance might have come a lack of trust, and it was for this reason no terms were entered into. With flexibility, however, also comes more chance of risk, so the development of a risk strategy was key.

For the purposes of the IL Bill work, press releases were issued with the Carers UK, EOC and DRC names attached. Within the DRC, the issue of blurring the messages of other areas of the DRC's work was a concern. It was understood that if the DRC shifted too far onto the other lobbies' ground they may lose some focus in the media and public eye on the wider messages they were putting forward.

It was perhaps this 'dilution of message' issue that proved to be the most internally contentious for the DRC. Given that the IL Bill was intended as an important part of the DRC's legacy, the danger of the IL Bill taking a broader approach towards social care and civil society would be to lose the key point of Independent Living for disabled people. At the same time, however, the process of delivering the campaign for Independent Living brought the DRC into contact with the wider debate for the future of social care and support. It thus soon became clear that the DRC either had to engage with the wider debate or face being left on the sidelines. Driven by the need to retain its position as an influential body, the DRC had to ensure that it strategically shifted to a bigger stage.

A further concern was whether the organisations that formed the alliance constituted the right mix. Firstly, it was suggested that the organisations were not influential enough; secondly, it was thought that the alliance was a 'congregation of supporters' who needed no convincing about the validity of the case for Independent Living rights, and thus watered down their clout. One suggestion had been that it would have been beneficial to engage with organisations who were overtly critical of the DRC's views and to use the IL Bill as an opportunity to convince them. A lesson learnt from this is that always working with your friends means that those opposed or critical to your policies may be even harder to convince.

Using the development of the initial draft of the Bill through a process of comprehensive stakeholder engagement was suggested as one way the DRC could have combated this 'congregation' issue. For example, older peoples' organisations who were not involved in the early stages of the Bill's development had a negative response to the Bill when it first appeared. Once such organisations were consulted with at the later stages of the Bill, they became happy with the outcome. Had a wider range of organisations been involved from the outset it is possible that a stronger alliance and hence a stronger Bill could have been developed from an earlier stage.

Forming the alliance: government

It was anticipated at the outset of the IL Bill process that the potential cost of recommendations would present the greatest stumbling block to its ultimate progress. To help the DRC overcome this barrier, economists were commissioned to cost the Bill, allowing the DRC to argue throughout that although costs are high up-front there are

long-term savings to be made (such as a reduction of reliance on expensive health services).

The economists' reports were developed in partnership with the Department for Work and Pensions (DWP), on the basis that as the government was so worried about costs, it was a better idea to work with them from the outset.

The benefit of this partnership was that it increased the money available to commission the economists' work and secure suitable economists to run the project – involvement which had previously been difficult to secure. Although there were undoubtedly benefits to the DWP's involvement at an early stage, there were also disadvantages to the chosen approach.

The major difficulty encountered was that the two initial reports received by the DRC at the end of November 2006 still remain unpublished. There is some concern by the DRC that this might be a delaying tactic by the DWP to stall the release of the findings, which might not be concurrent with their view of the true costs of the Bill. However, the DRC has now begun to use findings from the draft reports, quoting them in meetings and presentations. Whilst this is not as useful as a full release of a joint report, it does produce some benefit from having conducted the research.

Overall, clarity on what would be produced, and how it would be promoted should have been agreed at the outset. In this instance, a document outlining and agreeing publication dates of key outputs would have avoided this situation.

Looking to the future

Due to the short time left before it was to make way for the CEHR, the DRC developed a plan for pushing the IL Bill through using the efforts of the alliance organisations. The team working on the Bill looked to spend the last months of the DRC influencing the CEHR and other stakeholders, including the CEHR's Disability Committee, with a view to ensuring that Independent Living remains high on all agendas. Such an approach involves continuing to raise awareness of Independent Living and setting out its broader social and economic values, particularly for groups such as employers.

The DRC hopes that the strength of the working relationships between the partners will endure, and that the core ideals put across in the IL Bill, as directed by the DRC, will remain constant.