

Disability Rights Commission

Learning lessons:
The story of the
DRC Action Groups

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Executive summary

The Learning Narratives project contributes to the broad legacy strategy of the Disability Rights Commission (DRC). 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.

The story of the DRC Action Groups explores the background to, and development of, the Learning Disability Action Group (LDAG) and the Mental Health Action Group (MHAG)). Whilst considerable achievements and success stories have emerged from the hard work of all the DRC Action Groups over the past six years, this narrative will mainly focus on the history and workings of LDAG. The far-reaching achievements of MHAG over the past few years are also discussed.

The story of the DRC Action Groups: Key Lessons

Reflecting and representing constituents

- An organisation needs to reflect and represent its widest constituents. Establishing Action Groups is a proactive method of redressing balances where there is clear under-representation.

- An Action Group needs to reflect and represent its specific constituents. The DRC Action Groups were powerful as they were chaired by individuals with a (relevant) impairment.
- The DRC Action Groups have been powerful agents for change as the 'lived' experience of its members have provided a deep evidence base to inform policy and practice.
- The Action Groups should include members from relevant organisations eg learning disability and mental health groups. This provides a high level of credibility to outside stakeholders.
- Action Groups need to reach out and involve a broad range of stakeholders if they are to build strong partnerships to sustain change.

Organisational 'fit' and support

- To help ensure their success, Action Groups need a senior management 'sponsor' who will provide a clear bridge between the Group and the core business of the organisation.
- The Action Groups must have clearly identified business to address which are then linked to outputs.
- The work and outcomes of the Action Groups need to be clearly aligned to core organisation business so they become integral to delivery, rather than an isolated activity.
- If Action Groups are to be successfully integrated into an organisation it is important early wins are secured.
- Action Groups require dedicated resources, including staff such as Secretariat, if they are to be truly meaningful.

- It is important that Action Groups have a level of accountability in line with other functions in the organisation, as this ensures the Groups are not treated or perceived as tokenistic.

Action

- Action Groups need to be 'action' focused if they are to deliver real change.
- Action Groups need to have a dual role: they should act as agents for change internally, raising awareness and understanding of the impairment, whilst also having an external role in supporting wider changes.

Important considerations

- Action Group members should have access to relevant training as part of their own professional development. Staff in organisations require training focused on the particular impairment (or issue) of the specific Action Groups so knowledge and understanding is spread throughout the organisation.
- The DRC Action Groups worked because they eschewed traditional meeting styles, and instead developed protocols which best suited members.
- The language and terminology used should be agreed by the Group at the outset, and then applied consistently thereafter. For the LDAG, this included establishing Easy Read standards.
- DRC Action Groups were particularly good at providing space for social interaction between members, which had spin off benefits in terms of developing ideas and other projects.
- The underlying concept of all Action Groups should be: 'nothing about us without us'.

Introduction

The barriers faced by someone with epilepsy, someone with motor neurone disease, someone with schizophrenia and someone with profound learning difficulties are very different. It has been crucial for the DRC to understand and respond to such differences in order to achieve its vision of participation for all disabled people. **DRC Commissioner**

Shortly after the DRC opened its doors for business in 2000, it became clear that there were groups of disabled people facing barriers unique to their impairment who had felt historically under-represented within the wider disability movement. Whilst disabled groups such as those with physical disabilities had previously been highly involved in guiding service delivery, law and practice, other groups – such as those with mental health or neurodiversity conditions – had been given less opportunity to impact upon such areas of work. In response to this, a series of DRC-led Action Groups was set up from 2001 onwards with the specific aim of achieving the deeper involvement of disabled people with specific impairments. The birth of the DRC Action Groups is captured by a senior stakeholder as follows:

When the DRC was first conceived, there was a tendency to look towards the groups representing those with physical impairment as the main port of call for the views of disabled people. But as time went by it was clear that certain groups were not readily involved in our work and, in many cases, faced multiple disadvantages. It was decided to set up a number of groups that would explicitly engage those who were deemed disadvantaged.

DRC Commissioner

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The role of the DRC's Action Groups in championing the needs and perspectives of a range of people has been instrumental both in making change happen through the involvement of disabled people and in raising awareness of the DRC externally. In order to achieve its vision of 'a society where all disabled people can participate fully as equal citizens' there was a strong need for the DRC to respond to the differences in impairments and to encourage the government and other organisations to do the same.

The aim of looking at different experiences of impairment is not to divert the DRC into a multitude of highly impairment-specific pieces of work. It is rather to ensure that groups who are likely to be more excluded can have a voice in the disability rights agenda and properly influence the DRC's work. The aim is to build bridges, not power bases.

DRC paper for the Commission

Thus, the DRC established four Action Groups from 2001 onwards: the Learning Disability Action Group (LDAG); the Mental Health Action Group (MHAG); the NeuroDiversity Group and the BME Advisory Group. These Groups have been seen both internally and externally as vital and meaningful vehicles for enabling 'deep and ongoing involvement' in the work of the DRC and the wider policy agenda. Their work is exemplified by high profile documents such as the Coming Together report produced by MHAG, which has been highly influential in raising awareness of the steps required to enable mental health service users to contribute more fully to society.

The Learning Disability Action Group (LDAG)

LDAG is widely regarded as an effective Action Group, having succeeded over the years in engaging people with a learning disability in an ongoing dialogue with the DRC about the factors affecting their lives.

The first LDAG meeting took place on 19 June 2001, where the group was launched as an advisory group for guiding DRC policies and service delivery. The values of the group were initially very much aligned with the Valuing People White Paper published by the Department of Health (1999), which made key recommendations for change to services delivered to people with a learning disability in England. This paper succeeded in raising the awareness of the many challenges faced by people with a learning disability, who are often vulnerable and excluded members of society, making key recommendations for helping to overcome prejudice, bullying and discrimination. The non-visible nature of many learning disabilities highlighted in the White Paper was seen as the main catalyst in driving forward the need for a dedicated DRC Action Group for people with a learning disability.

If you have a physical disability, then it is clear for everyone to see and people are aware of many of the challenges you face... for learning disabilities it is less obvious. If you don't have a learning disability, you don't know what it's like and what we find challenging in everyday life. It's different to other disabilities, so we need to be listened to and we need to have a voice for change. **LDAG member**

An early discussion amongst members of LDAG focused on whether they wished to refer to people as having a learning disability or a learning difficulty. Some discussion and debate was had around this issue, leading to the final decision being put to a vote amongst members. This process resulted in the decision to use the word disability both for the name of the group and for all future references within all their meeting minutes and publications.

From advice to action

The initial remit of LDAG was to provide a two-way dialogue between the group and DRC Commissioners to provide informal advice and guidance on producing accessible public materials, DRC guidance and Helpline support that was sensitive to the unique needs and barriers faced by people with a learning disability. However, within 18 months of the start of LDAG's quarterly meetings, a number of notable achievements had already come to fruition in affecting internal change within the DRC. An example of this is the visits made by LDAG to the DRC Helpline in Stratford to raise awareness of the unique barriers people with a learning disability face when trying to make contact. The installation of videophone technology and the implementation of novel web-chatting devices were just two of the Helpline developments to result from these visits by members of LDAG. Similarly, appointment booking systems were also made available in Easy Read.

A series of other early internal developments led LDAG to move rapidly on from focusing on service provision to becoming more outward-looking and ambitious in their approach. The focus of LDAG meetings therefore moved on to addressing more fundamental policy issues, with the aim of working towards removing the numerous external barriers preventing people with a learning disability from living their lives to the full. Members and visitors to the quarterly LDAG

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meetings recall the development of an atmosphere of 'action', in which members became very quickly focused upon outcomes and effecting real change for the lives of people with learning disabilities. A conscious effort was made to maintain a positive focus on making a difference in the future, rather than dwelling on the inequalities and injustice faced in the past.

This really is an 'action' group in its most raw form... it is so easy for groups such as this to slip into moaning and complaining about current or past failings and get swamped by a bitter outlet of emotion... but by keeping focused on concrete positive outcomes for the future LDAG has managed to keep active and drive forward to overcome these barriers. **LDAG member**

Group membership

Establishing the membership of LDAG was subject to a number of constraints and considerations, despite initially operating on a relatively informal invitation basis. Firstly, it was deemed to be of fundamental importance that the group be entirely populated by people with a learning disability. For example, the Chair of LDAG was a Commissioner who had a learning disability. Second, both the Chair and the DRC's Lead Officer for LDAG (a member of the DRC's Senior Management Team) were keen to guarantee a good representation of members with a range of learning disabilities to ensure that individual issues unique to certain disabilities could be fed into the group. It was also deemed important to invite senior members from well-known and respected organisations, such as Mencap and People First, both to maintain a high profile in the disability equality field and to allow for external guidance for the work of the DRC. Other considerations included the assurance of a good

gender balance, appropriate BME representation and Great Britain-wide membership to allow issues specific to England, Scotland and Wales to inform the actions and outcomes of the group.

The number of members of the group has remained about the same since 2001. Some 'founder members' still sit on the group, whilst those who would now like to join form a short waiting list. Whilst a more formal appointments process would now be necessary for an Action Group with this level of recognition, key learning can be taken from the success of a group with such a diverse range of backgrounds and experience. The positive and productive dynamics of the LDAG membership is considered by many to have been fundamental in contributing to the successful cohesion of the group on both a professional and a social level:

LDAG has transformed into a social group as well as becoming an Action Group at the same time... the fact that we all get on so well has greatly helped the productivity of the group, and there have been friendships made amongst members which will long out-live the death of the DRC. **LDAG member**

A key area of strength for LDAG has also been the support of a Lead Officer and staff member in the Secretariat to ensure that the group meetings are minuted, well-organised and planned in advance to involve guest speakers and senior staff from the DRC. This has allowed for all minutes from the group to be presented on the DRC website in easy-to-access formats, enabling people to track and monitor the resulting actions taken by the DRC. Finally, the appointment of a group Chair with a learning disability herself has been seen to be highly symbolic of the LDAG mission of making change happen – as led and directed by people with a learning disability themselves.

The involvement of people with a learning disability

From an external perspective, visitors to LDAG have been impressed by the way in which the group has worked hard to enable members with complex disabilities to contribute to meetings and succeeded in actively engaging all attendees in discussion. This is thought to have played a powerful role in ensuring that those facing the most complex barriers are able to feed into the workings of the group:

I observed in one meeting the use of pre-programmed voice-boxes to allow a person with complex impairments to feed into discussion... members were very flexible in working to support this contribution, and efforts put into the prior preparation meant that this person received the meeting agenda and materials in advance and was able to prepare their thoughts and answers to feed into the meeting. **External group visitor**

The passion of LDAG members has also encouraged other DRC Action Groups in driving forward and raising awareness of overlapping issues. A particularly strong relationship was formed early on between LDAG and MHAG as a result of the notable overlap of important issues affecting both people with a learning disability and survivors of the mental health system. Particular areas of overlapping interests between LDAG and MHAG have included: access to justice; issues affecting carers; employment; advocacy; and poor social services. Regular communication and yearly meetings between LDAG and other groups (such as MHAG) has

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allowed for the sharing and development of ideas, as well as the monitoring of progress. Furthermore, the forward-thinking nature of LDAG and the extent to which it has supported and encouraged people with a learning disability to take a political lead has influenced the work of MHAG and other groups:

For issues such as capacity, which affect both MHAG and LDAG, I have been very impressed by the concern and passion of LDAG members in driving forward arguments which have consequently infiltrated discussions within our group. LDAG really is a great example of a group which allows people with learning disabilities not only to drive relevant issues forward, but also to take the lead in doing so with confidence. **MHAG member**

The involvement of people with a learning disability

The work of LDAG over the past few years has been far-reaching and diverse. There are countless illustrations of the positive impact LDAG has had on the lives of people with a learning disability which have resulted directly from the passion and dedication of the group's members. Both LDAG and MHAG have been mentioned in the Houses of Parliament, which has been both beneficial to the DRC's legacy and for the power and authority of its individual groups internally.

The greatly increased presence of learning disability issues externally and internally on the DRC agenda since the group first formed is a reflection of the power and influence LDAG has achieved.

DRC member of staff

Examples of areas where the work of LDAG has made a difference include taking forward issues surrounding the creation of better GB-wide signage, factors affecting the voting rights of people with a learning disability and their involvement in emergency planning and disaster recovery. The provision of guidance has also been a big role for LDAG, having produced guides for local government and other organisations to ensure their service provision is sensitive to the needs of people with a learning disability. Further areas of notable achievement include:

- Work with Liverpool Social Services to support victims and witnesses of crime in making court appearances,

and supporting the Crown Prosecution Service in promoting witness profiling.

- The production of an Easy Read report focused on Human Rights expressing the thoughts, opinions and concerns of LDAG members about issues such as the allocation of funds to support independent living, hospice care and euthanasia.
- Work with the Commission for Racial Equality (CRE) and Valuing People to write a published guide to help local Learning Disability Partnership Boards work well with people from a black or minority ethnic background who have a learning disability.

However, there are a number of areas in which the hard work of LDAG members has led to change which has been ongoing and widely acknowledged. These are outlined in turn below as described by members of the group, external visitors to the group and staff more widely at the DRC.

Accessible information: Easy Read

The crucial importance of involving people with a learning disability in creating Easy Read standards and guidance work cannot be over-stated by those involved in the work.

From the point of view of someone producing a document who doesn't have a learning disability, it is impossible to know what people with learning disabilities will struggle with. This makes it vital to involve and get advice from people with a learning disability in guiding and mainstreaming the importance of getting Easy Read right.

LDAG member

To address this issue, an LDAG Easy Read sub-group was set up in 2002 to work with the DRC's Marketing team on national standards for Easy Read publications. This group has been

responsible within the DRC for raising the profile of Easy Read as an essential factor in ensuring that all publications are accessible to people with a learning disability. This sub-group has made huge advances both in guiding the DRC in its publication of Easy Read materials and putting pressure on government departments to comply with the standards required for publications to be accessible. Particular progress was noted in the awareness and actions of the Department for Work and Pensions and the Department for Constitutional Affairs (DCA) with regards to the production of Easy Read materials.

The DRC and other organisations are now more aware that the need for Easy Read is a big issue for people with learning disabilities, and that it's not an optional extra. This is largely down to the work of LDAG. **DRC member of staff**

Banking

Increased government focus on the financial inclusion of people with a learning disability followed the 2004 report 'Promoting Financial Inclusion' published by the Treasury. Following this report, LDAG made great advances in raising awareness of the barriers faced by people with a learning disability both in accessing banking services and managing their own long-term finances. The number of current policies and practices, such as the direct payment of benefits, requiring people with a learning disability to have their own bank account has placed them firmly within the financial market place and in need of appropriate services from the banking industry. Barriers to accessing and managing bank accounts have therefore had a huge impact upon the capacity of people with a learning disability to receive, for example, Independent Living Funds (ILF), payment from employment, direct payments and so on.

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After raising the importance of this issue in an early meeting, LDAG soon became aware of the high level of anxiety surrounding the issue, partly because of the number of other organisations focusing on financial barriers for people with a learning disability. The group was proactive in joining forces with the Association for Real Change (ARC) in hosting a one-day seminar to bring together all organisations and statutory bodies interested in moving this issue forward. This seminar succeeded in combining a range of expertise and motivation in the field, which created a wealth of useful outcomes and actions towards making a difference in this area. In order to enhance their power and position for influencing top banking societies, LDAG also involved the Employers' Forum on Disability to make use of their high-profile reputation for focusing on disability and enabling change in the private sector in a supportive rather than challenging way.

As a result of this work, LDAG – in partnership with the ARC and Valuing People Support Team – produced a report called 'Access to banking services by learning disabled people for the British Banking Association (BBA)'. The report coherently explains the real-life challenges faced by people with a learning disability around access to bank and building society accounts, and outlines achievable goals for banks to work towards regarding increased flexibility, provision of Easy Read versions of complex banking materials and the proactive marketing of information for people with a learning disability about Chip and Signature cards.

The Mental Capacity Act

After the high-profile 'Bournewood Case' revealed a hole in the law that allows individuals with learning disabilities in Europe to be locked up in mental health units without consent, the Mental Capacity Act was passed in 2005 to protect people's rights. LDAG had a significant impact in its work with the Department for Constitutional Affairs (DCA) on this Act. Due to the tireless work of LDAG (and others) the original focus (and title) of the law was moved away from incapacity and towards capacity. As a result, the essence of the law has now been changed so that organisations in the state and private sector must always assume capacity, unless proven otherwise. The collective work of LDAG and others was also responsible for persuading the DCA to legislate for ring-fenced resources to provide comprehensive Independent Mental Capacity Advocacy services throughout the country.

This is the area where LDAG has really come into its own as a campaigning and lobbying group to effect change on a wide scale. It is amazing to see real change that will affect the lives of countless people with a learning disability, just by raising awareness and understanding of our needs with people in positions of power. **LDAG member**

In 2004, members of LDAG were proactive in arranging to speak with the relevant Minister of State to express their concerns that the Mental Capacity Act was not likely to take into account complex issues unique to people with a learning disability. Several actions followed this meeting, including the agreement that the Act would be available in Easy Read

and verified with a group of people with a learning disability before publication. Additionally, all material designed for end users have been, and will continue to be, made available in Easy Read format.

Transport

In response to a number of barriers faced by LDAG members in using the British transport system, the group dedicated energy to exploring ways in which access to trains, buses and taxis could be made easier for people with a learning disability. Particular difficulties highlighted were those associated with automated systems such as the Disabled Person's Reporting System used to book support when travelling on a train.

In May 2004, LDAG invited representatives from Virgin, First Great Western and the Association of Train Operating Companies to meet in order to raise awareness of such difficulties and explore what could be done to make a difference. An initially confrontational meeting was transformed into a productive planning session in which actions were transcribed to be sent to the Transport Thematic Director.

The meeting was very powerful and productive... it started off as being quite confrontational, but once the transport reps got the chance to actually see and hear first-hand the challenges we were coming up against they were more willing to listen. Some of them had clearly never considered the system from the point of view of a person with a learning disability. **LDAG member**

LDAG has also heavily influenced the DRC's GoJo campaign on public transport, which focuses on the confidence of young disabled people to use public transport such as buses, trams and trains.

The Right to Vote information pack

LDAG has carried out extensive work with Valuing People to work towards helping people with a learning disability to register to vote for local and general elections. A Right to Vote information pack was produced in 2005, in partnership with Valuing People, as a comprehensive guide to help people with a learning disability, their supporters, parents and carers in the voting process. The pack includes advice and guidance about how to register to vote, what to do at the polling station and how to become more politically active on a wider scale. It was launched in both Houses of Parliament, and the Polls Apart campaign showed a significant increase in people with a learning disability voting in the general election following their work. The Right to Vote information pack was also made 'open source', with all copyright removed to encourage other organisations to adapt and use it for their own purposes. Evidence of the value of that move was shown by Enable amending and using the pack for the most recent elections to the Scottish Executive.

The Mental Health Action Group (MHAG)

People with long-term mental health conditions face some of the most severe exclusion in Britain, including an 80 per cent unemployment rate and a high likelihood of dying young. The Mental Health Action Group (MHAG), with its unfailing commitment towards full citizenship for people with mental health conditions, has made considerable progress across a wide range of areas in the past few years, spreading awareness of the unique barriers facing people with mental health conditions. The group has worked tirelessly to promote the idea that 'disability access' is relevant for people with mental health conditions through wide-ranging guidance and good practice.

At meetings of MHAG, the members feel relaxed because they can discuss and share information in an atmosphere where confidentiality is respected and where everyone is committed to treating them with respect and as multi-faceted individuals, not just a person whose foremost characteristic is to 'be mentally ill'. **DRC member of staff**

In 2003, MHAG produced a key report: 'Coming Together – mental health service users and disability rights', which has recently been updated with key recommendations for the CEHR. The report covers a broad spectrum of areas including access to justice, education, employment, transport, refugees and asylum seekers and discrimination in health services. This work has helped to build bridges to contribute to the DRC goal of letting more disabled people know about their rights, including those who may not view themselves as disabled people. This report has also been welcomed by

external commentators for breaking new ground in outlining a disability rights agenda as it applies to mental health service users. During the debate on the planning of the CEHR, for example, MIND made a public statement supporting the work the DRC was doing to include mental health considerations.

MHAG has also helped in beginning to alert wider groups of mental health service users and workers to debates that go beyond treatment and care. For example, the group has looked to establish a focus on the daily reality of social exclusion for mental health service users and the significance of citizenship and rights. Speeches have been delivered to major employer audiences highlighting good practice in employing, and making reasonable adjustments for, people with mental health conditions. Leaflets and CD-ROMs produced in consultation with the group also include a guide for trade unions and a hard-hitting film called 'The Appointment', which reflects the reality of having to conceal health conditions at work.

MHAG has also been highly successful in terms of informing DRC media and policy-influencing work, ensuring that materials reflect the reasonable adjustments that can be made for people with mental health conditions. This work has positioned the DRC positively with mental health service users and their organisations, which has not always been achieved historically by pan-disability organisations.

Further achievements of MHAG

MHAG has also played a large part in informing the major DRC investigation into health inequalities experienced by people with mental health conditions and/or learning disabilities, by providing evidence and examples of the problems encountered by mental health service users. This involved hundreds of people with personal experience of

mental health conditions and has fed into government policy and practice in England and Wales.

Other areas of notable achievement for MHAG include:

- Work on Independent Living, including developing a language on access and independent living that works for mental health service users and survivors.
- Advising the DRC on its services and legal work in relation to clients with mental health conditions, including advice on legislative changes, which resulted in the Government making the DDA fairer to people with mental health conditions in 2005.
- Hosting a consultation session for the Social Exclusion Unit (SEU) which fed into the DRC response to the SEU's inquiry. This influenced the SEU's thinking in relation to keeping the DDA under review, given low success rates at tribunal amongst mental health service users.

MHAG has greatly benefited from the close involvement of Commissioners and from the leadership of its Chair. One part of MHAG's success is the personal experience of the Chair's long-term mental health conditions and the way in which she is enabled to act as Chair by the provision of strong support from the secretariat and personal assistance.

It is unusual for people with current serious mental health difficulties – rather than past experience – to be so actively involved. The group includes a wide range of experience and expertise and the individuals have gelled and work well together as a group. **MHAG member**

What about the future?

Of vital importance is the continuation of the work of the Action Groups, and to have this sort of proper and regular involvement of people with a learning disability in a way that genuinely brings about change. **LDAG member**

There is widespread consensus over the continued need for Action Groups focused upon the unique needs of people with a learning disability and people with mental health conditions. LDAG members, MHAG members and external visitors alike believe it is vital that the work of the DRC Action Groups is continued in the move to the CEHR. Of particular importance is the ability of these distinct groups to enable discussion and action focused specifically on the challenges posed by different impairments, allowing for invaluable guidance and input from those who have direct experience of the challenges faced. To lose this focus would be to lose the potential to champion positive and focused change across a wide spectrum of disabilities.

It is absolutely crucial that the CEHR has an Action Group with a discrete learning disability focus as part of the wider disability agenda, as there are discrete issues accompanying learning disabilities which need special attention. **External group visitor**

Members of the DRC's MHAG have an ongoing commitment to full citizenship for people with mental health conditions. We are not visiting the experience of exclusion; we live here. Ongoing advice to the CEHR on mental health will be vital to its success. **Coming Together report**

The Action Groups have identified areas where further work is required. This includes a focus on Human Rights issues and Independent Living for people with a learning disability. There is also a call for scrutinising the Disability Equality Duty (DED) and Disability Discrimination Act (DDA) to ensure that they do not lose sight of the issues affecting people with a learning disability or mental health condition.

There is so much still to be done, and we must never stand still – there is a long way to go on issues surrounding carers with a learning disability and the support they need, and the DRC has only just started taking that on. Every day people with a learning disability are having their children taken away from them... we have to continue to fight in so many areas, and keep the momentum we have begun with LDAG. **LDAG member**

MHAG has unfinished and continuing work around discrimination in mental health, whereas the neurodiversity group has much work moving forwards around access to public transport and mainstreaming of awareness of the challenges facing people with neurological impairments. The words of advice from a current member of LDAG for all future members and leaders of an Action Group such as this reflect the commitment and drive of those powering LDAG during the last six years:

Work hard, make your presence felt, involve people with learning disabilities in decisions, and listen to other Action Groups. Action Groups want more commitment to policy making. Decisions should be made more equally. **LDAG member**

Key learning for the future

Whilst there are clearly numerous areas of achievement for LDAG and MHAG, there are key areas of learning highlighted by those involved with the groups to be taken forward to the future. These are outlined below.

Training

Further training is still required to raise awareness around less widely-appreciated disability challenges such as those covered within the Neurodiversity Action Group. It is thought that this will help in mainstreaming the issues involved and creating a network of support for actions implemented by the different Action Groups:

If the DRC or other bodies don't understand these issues – which are not directly visible – then what hope have we got that we're going to get any change? When you look at the vulnerable areas of society, you find the largest cohort of people without any support. It needs to be the role of the neurodiversity group to change that.

External group visitor

Innovative meeting styles

Whilst LDAG has principally operated by traditional meeting rules involving round-table discussions, in some circumstances a more informal style of working in the future might enable members to participate more freely and imaginatively in discussion. The use of different meeting techniques such as breaking up into small groups and, for

example, having members move from table to table, are all predicted to enable deeper engagement and facilitate more innovative actions in the future.

Accountability

An appropriate structure of accountability for Action Groups would be required within the future sponsoring organisation to prompt transparency, action-monitoring and create an external drive to maintain progress. Accountability for the Chairs of Action Groups is thought to be of particular importance, alongside the capacity to offer organisational support for this influential and challenging role:

It is vital that a group such as LDAG has the appropriate accountability and support it needs and this will require clearly dedicated capacity within the organisation. The Chair is the key point of contact between the group and the Commissioners and wider organisation, and they need to be appropriately supported and directed in this position. **LDAG member**

There is also a strong feeling that the terms of reference from the sponsoring organisation must be clear and concise and encourage action rather than advice.

Partnership working

It is vital for Action Groups to work more productively in partnership with other significant players who are working towards making progress in the same priority areas. Accessible information and transport issues are obvious areas where Action Groups can both share learning and experience with other organisations, and join forces to generate more powerful means of influencing future policy.

Inter-group relations

There is a strong consensus amongst group members that the channels of communication between all the internal Action Groups and the Commissioners need to be strengthened and maintained. Regular feedback of activities and progress by Action Group representatives at Commissioners' meetings will continue to be fundamental to ensuring that the work of the groups is mainstreamed internally and that the potential for the cross-fertilisation of action areas is maximised.

Conclusion

Action groups, such as LDAG, are just so important because they allow individuals with a learning disability to speak for themselves. There is no better way of influencing and allowing leaders in the field to emerge and inspire others.

Dame Jo Williams, Chief Executive, Mencap

LDAG has actually changed disabled peoples' lives for the better. Being part of the group has given me the confidence to speak up using a communication aid for the first time, and I've been privileged to be part of such a powerful group. It should definitely continue in the future.

LDAG member

The aims of LDAG and MHAG over the past six years have been simple: to work towards making sure that everyone with a learning disability or a mental health condition plays as full a part in society as they can. Nowhere else is there such a powerful example of positive change as lead and directed by disabled people themselves.

Getting the input of these separate groups facing unique barriers and challenges has been vitally important – the members of these groups are people who are committed to working together as part of the disability movement, and when this energy is channelled in the right direction it can lead to great things.

MHAG member

This narrative is most appropriately ended by the one sentence which captures the essence of what these Action

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Groups were designed to achieve. Without the meaningful involvement of members whose lives are affected every day by the barriers they face, the progress made to overcoming those hurdles is likely to be significantly diminished.

'Nothing about us, without us'