

Disability Rights Commission

Learning lessons:
The use of evidence
in the DRC

Contents

Executive summary	Page 2
Introduction	Page 5
The importance of evidence to the DRC	Page 6
DRC Library & Information Services (LIS)	Page 7
The purpose of LIS	Page 10
The DRC Research function	Page 13
LIS and Research working together	Page 15
An example: the Health Inequalities Formal Investigation	Page 16
Concluding remarks	Page 19

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 what has made for an effective working and inter-linking relationship between the Library & Information Service and the research function at the DRC. Some of the main lessons are exemplified through a case study of the DRC's Health Inequalities Formal Investigation.

The use of evidence at the DRC: key lessons

Library & Information Service

- It is important for an organisation to correctly position its Library & Information Service – not physically, but organisationally – since this will allow for the most efficient sharing of knowledge to relevant staff
- A library and information service is important for both internal and external users of an organisation.
- LIS can act as a conduit between all aspects of the work of an organisation, and securing the right information in a timely fashion and making sure it gets to the right people at the right time is the key to this.

- The structure of a library service along thematic lines (or those that meet the strategic needs of an organisation) and the distribution of information along these lines is key, and ensures all relevant people working on a theme receive the right information
- Internal self promotion is an important role of any LIS. By letting individuals and teams know what it can do for them, LIS ensures maximum effect.
- Sending out awareness bulletins and the use of a relevant news portal on an Intranet are effective means of self promotion.
- An LIS can draw people in who would not necessarily have contact with an organisation otherwise. This can therefore help promote an organisation to others outside its immediate sphere or field.

Research

- Research undertaken in an organisation should be aligned to its strategy, which could therefore allow the LIS and Research teams to complement each other's work.
- To meet diverse needs for research evidence, an organisation could:
 - Move away from broad literature reviews to focused reviews, creating greater potential for publication and media coverage.
 - Emphasize the participation and perspectives of disabled people – or other key stakeholders – and 'what works' instead of concentrating on theory.
 - Focus more on networking and influencing other organisations – including government – in order to

mainstream relevant questions – such as those concerning disability rights – in the work of others.

- For a GB-wide country, having dedicated research teams within Scotland and Wales, and therefore an evidence base which is geographically relevant, can mean more influential and appropriate cases can be made to the relevant decision- and policy-makers.
- Working together, LIS and research teams can identify what is known about a topic and help determine whether other work can or should go ahead as a result.
- Knowing what the likely audience is for a piece of work should help inform the level of rigour and approach taken in any piece of research
- If research is prompted by the lack of evidence in an area, then one of the end results of the research should include recommendations as to how this issue of lack of evidence can be addressed in a sustainable way.

Introduction

The DRC uses evidence and knowledge to inform many strands of work such as policy, communications and media. This narrative will look at how this robust information gathering and knowledge management has benefited the organisation and helped the DRC enforce and campaign for the rights of disabled people.

The narrative will describe the two functions primarily responsible for gathering and disseminating evidence in the DRC: the Library & Information Service (LIS) and the research department. The combined efforts, links and methods employed by these two teams are explored and the health inequalities formal investigation conducted by the DRC used as an illustrative example.

The importance of evidence to the DRC

Evidence-based decision making is central to the DRC and has been fundamental in developing important strands of work, including substantial recent pieces of work such as the Disability Debate and Agenda, the Independent Living Bill and the DRC's Legislative Review.

To have a good evidence base means that everyone working in an organisation knows that when statistics are quoted or claims are made they can be backed up with sound research. **Member of LIS staff**

DRC Library & Information Services (LIS)

The DRC's LIS is headed by a Service Manager, with the part-time professional support of an assistant librarian and two part-time administrative officers.

The main DRC Library is located in the Manchester office, with smaller core reference collections at all other sites. The LIS offers the full range of library / information services including:

- Lending facilities
- Coordinating journal and electronic database subscriptions
- Inter-library loans
- An enquiry / request service to all staff and Commissioners
- Literature searching and bibliographies
- Maintenance and promotion of a Knowledge Centre on the Intranet
- A weekly 'Essential Reading' bulletin
- Targeted current awareness services
- Maintenance of the Disability News and Equalities and Human Rights pages of the Intranet
- Responsibility for the DRC's FOI Act Publications Scheme and archiving work.

To illustrate the scope of this work, in 2006 / 2007 LIS issued 1685 items, dealt with over 7000 individual requests, and received over 1800 visitors.

The resources within the library are organised along the lines of education, employment, health and independent living, and transport, goods and services – in line with the DRC's Strategic Plan. The strong link between the strategic aims of the DRC and the information received by the library means that new articles, books and knowledge received can be targeted easily and effectively to the right people in the right place at the right time.

Positioning an LIS function

The importance of positioning the LIS function within an organisation, not physically but organisationally, is key to a successful and useful service. The location of an information function should allow the most efficient sharing of knowledge and careful thought is needed as to where in the wider corporate structure this location is.

Initially LIS was situated within the Resources directorate of the DRC, alongside departments such as Human Resources, Finance and Facilities. Indeed the LIS was originally part of the ICT team. The library operated from this directorate until 2005, at which time the linkages between the LIS and other functions of the DRC were recognised as being much stronger than those it held with the Resources directorate. LIS therefore put forward a business case for its realignment to the Policy & Communications directorate – a proposal which was strengthened by the ability to call upon key lending and usage statistics of the LIS and which was accepted.

The main outcome of this realignment was an increased role in informing and supporting the research and evidence

Learning lessons: The use of evidence in the DRC

base in policy and communications. These work areas were key library customers – along with the Legal directorate – and though there was no physical change in location, these important organisational linkages were strengthened by this shift. The LIS could therefore deliver a better product to those who used it most.

The purpose of LIS

The major roles of the Library & Information Service can be divided into how it serves internal users and how it also provides external benefit for the DRC.

Internal: Keeping the intelligence high

Internally, LIS must keep the intelligence of the organisation 'high'. It achieves this by providing relevant articles, reports and other publications to the DRC, and in particular to the DRC's Senior Management Team, legal team, research function, media and communications teams. In providing this service, LIS always aims for proactive selection and dissemination of information.

The LIS's efforts to keep the whole of the DRC up-to-date with current thinking are essential. LIS is a conduit between all aspects of the work of the DRC, and securing the right information in a timely fashion and making sure it gets to the right people at the right time is the key to this. Customer feedback the library has received says that this is an area of success for the library:

Perfect timing, needed just that, right now.

Member of DRC staff

An important element of this timely information is the structure of the library along thematic lines and the distribution of information along these lines. This structure ensures that everyone working on a theme receives the same information, thus strengthening both the intelligence and the links between these individuals in what can often be a complex working environment.

Internal self promotion is also an important role of the LIS. By letting individuals and teams within the DRC know what it can do for them, LIS ensures maximum effect. This is achieved through awareness bulletins and a Disability News portal on the Intranet. In addition, the list of new articles abstracted from relevant journals which is circulated on a weekly basis across the organisation is 'religiously read' (according to one user) and is intended to provoke wider reading and thought around disability issues.

(The list) directs me towards issues to which I would not have access otherwise. **Member of DRC staff**

External: Promoting the DRC

It has also been vital for the LIS to keep external stakeholders up to date. External individuals and organisations are updated by the LIS on developments in the disability field in many different ways. These include weekly and monthly bulletins, a regularly updated current journal article reading list on the DRC website and a the 'Partnerships' newsletter.

To think of the purpose of the LIS as being both internal and external is a crucial point and a key development in the life of the DRC LIS. Historically, the LIS was very good at developing linkages internally between areas of the DRC by using the thematic structure – but the same connections were not being developed with external stakeholders. Once the potentially high benefit of this was realised, efforts were made to put the LIS on the radar of people across the equalities sector that were making decisions and needed evidence and resources.

Previously they may not have thought of the DRC as a place to go to but through self-promotion they have moved into this field and are now considered a substantial source of information for many external organisations and individuals. **Member of LIS staff**

Learning lessons: The use of evidence in the DRC

One area this has had particular impact is in promoting the DRC to organisations outside of the disability field, for example social care. As such, the LIS function has been used as a communication and promotional tool, and has been able to draw people in who the DRC would not necessarily have had contact with otherwise.

LIS is not really a physical library – it is so much bigger than that – it brings people together. Only part of its role is to do with evidence, and part of it is to do with drawing people together. **Member of LIS staff**

The DRC Research function

The DRC research team's aim is to produce authoritative evidence to support the DRC's vision of a society where all disabled people can participate fully as equal citizens. As in LIS, the research undertaken is aligned to the DRC themes and this importantly allows the LIS and Research teams to complement each other's work.

DRC Research meets a range of internal and external needs. Evidence produced is used not only to underpin policy formulation and wider communications functions, but also to influence more widely in the disability and related fields.

To meet the diverse needs for research evidence, the DRC revised its research strategy in a number of ways:

- A move away from broad literature reviews to more focused literature reviews. The rationale behind this is that focused studies have greater publication and media potential than wider literature reviews
- An emphasis on investigating discrimination and participation from the perspective of disabled people and focusing on 'what works' rather than theory
- An increased emphasis on networking with and influencing other organisations, including government departments and major charitable and academic research bodies/programmes, with the aim of mainstreaming disability rights questions into their work.

Cross-nation research

The issue of cross-nation research is one that the DRC has faced with mixed results. One issue with developing evidence across different nations is that much of the officially published government research that is available in England, say, is not available or relevant to Scotland and Wales. Governmental organisations focus more on the issues of relevance to the DRC in England and thus research is also focused in this area. Although it is important for some research to be GB-wide, there is also a need for dedicated research within Scotland and Wales.

One way of addressing this is to develop a substantial geographically-relevant evidence base in order to influence the relevant decision makers. Currently, both DRC offices in Scotland and Wales have a smaller inner circle of high level decision makers on disability issues. Such policy makers can therefore be reached and influenced by desired messages, therefore, with relative ease and the more geographically relevant these messages are, the more impactful they will be.

LIS and Research working together

In identifying challenges and overall areas of interest for the DRC to consider, LIS helps to identify and disseminate information on topics in the business and strategic plans, reported in media, relating to evidence, good practice and social trends, or raised by stakeholders. However, there needs to be a balance between information provided proactively and reactively, given resource constraints and the need to ensure that information is relevant and recipients are not overloaded.

Once the possibility of specific research projects is raised, LIS helps to establish how much is currently known (from a variety of sources, including research carried out elsewhere), to enable others to determine if a research project or other evidence gathering should go ahead. LIS also actively supports individual research projects by circulating new information (eg from other library databases, government, and media announcements) and responding to requests for either specific published reports or papers, internal DRC material, or broader enquiries. Although not a formal arrangement, the LIS–Research relationship models the attachment of a ‘knowledge officer’ to the project team. The current relationship is potentially also indicative of moves towards a broader knowledge-sharing culture within the organisation.

An example: the Health Inequalities Formal Investigation

An example of how developing and knowledge-managing an evidence base was put into action is provided by the Health Inequalities Formal Investigation.

This investigation was conducted between 2004 and 2006 and involved looking comprehensively at inequalities experienced within primary healthcare by people with mental health conditions or learning disabilities in England and Wales. Some 18 months of DRC work were channelled into this investigation across a range of functions, and this section of the narrative will focus specifically on the efforts made by the Research and LIS teams at each stage along it.

Identifying the research gap

The first step of the process was to identify gaps that exist in thematic areas of the DRC. In 2004, those working in the Health & Independent Living theme noted that anecdotal evidence was available regarding health inequalities experienced by disabled people.

In order to explore the issues further, a member of the research team therefore met with LIS in order to identify other relevant information, using appropriate keyword search terms. The centrality of LIS to the process secured from the outset good relationships with others working on the project and across the theme.

The results indicated that there was a substantial body of evidence already available, which justified a fuller investigation by the DRC.

The research role within the investigation

The Investigation itself was led by the Strategic Enforcement Unit, with input from the Research team. Initially, the role for the Research function was to manage a small number of research projects to contribute to the wider investigation. As the investigation progressed, however, it became apparent that research needed to play a central role. The DRC researcher therefore spent an ever-increasing proportion their time on the Investigation, particularly in identifying research needs and how these could be met.

Robust research evidence and peer review were critical to the value of any research for the audiences likely to be interested in the investigation. For the work to have the impact hoped for, it needed to be robust in terms of its methodology so that the medical and wider healthcare community could have confidence in it.

As a result, it was therefore vital that, when evidencing reports where success hinges on the rigour of the research, it was advisable to include representation from the Research team at each stage from project set-up to marketing.

An on-going tailored service was provided by LIS throughout this stage to the lead researcher on the investigation. The key to this was to be proactive and to understand what was needed at each point of the work. Searches were set up and email alerts sent as relevant information / evidence came to light or was located.

Working with external contractors

The research included a literature review, carried out internally, and the following pieces of external research:

- Analyses of primary care records
- Detailed Area Studies examining local clinical data and using interviews and focus groups to collect different perspectives on experiences of primary care
- Two literature reviews examining the effectiveness of interventions to improve physical health
- Secondary analysis of data on health checks for people with learning disabilities, together with additional qualitative research in Wales

The final project report was underpinned by the evidence gained through these studies, without which it could not have been sufficiently authoritative.

Sustainability

If research is prompted by the lack of evidence in an area, then ideally one of the end results of the research should include recommendations as to how this issue of lack of evidence can be addressed in a sustainable way.

In this example, the Investigation report specifically highlighted the need for the Department of Health, Primary Care Trusts and Local Health Boards to gather, collate and analyse data systematically in the future.

Our report analysed the situation in 2006 but evidence-gathering is an ongoing need. **Member of research staff**

Such data collection – identified as not currently satisfactory by the investigation – is essential if the health inequalities experienced by disabled people are to be monitored and addressed.

Concluding remarks

Evidence-based decision making has formed a key part in the development and delivery of the DRC's work. Central to the identification and dissemination of this evidence has been the DRC's Library & Information Service and the research team.

Whilst aspects of each team's individual work are important, their working together – in identifying what knowledge exists and where the gaps are, shaping potential areas for work as a result and providing crucial expertise for such work as it develops – contributes a powerful and rigorous platform, upon which the authority of much of the DRC's work is built.