Research Toolkit for Disabled People's Organisations:
How to undertake and use applied research

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Foreword

There are a number of very good manuals and texts on how to do research, including applied research and participatory research. However, we have found very little guidance available for advocacy groups, such as disabled peoples' organisations (DPOs), on what comes before and after research is done. This handbook addresses this gap, providing practical information for DPOs on why they might decide to undertake research, how to identify who to work with, how to guide the process to ensure they obtain results that are useful for them and what do to with their research findings.

This toolkit has been developed as one component of the DFID funded Cross-Cutting Disability Research Programme (CCDRP) undertaken by the Leonard Cheshire Disability and Inclusive Development Centre, University College London. You can find out about more about the programme at www.ucl.ac.uk/lc-ccr.

Copies of this toolkit can be obtained online at:
www.ucl.ac.uk/lc-ccr
or www.lcint.org

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I AM CALLING ON PARLIAMENT TO RATIFY THE DISABILITY BILL AND THE UN CONVEN ON PERSONS LIVING WITH DISABILITY WITHOUT DELAY.

Chapter 1

How to use this toolkit

This toolkit is designed as a practical resource for disabled people's organisations (DPOs), particularly those working in the global South, on **how to use research knowledge** in their programmes, campaigning and advocacy work.[1]

This is not a toolkit about **how to do research** (although Chapter 4 provides an explanation of different types of research and the methodologies that can be employed). There are many books, manuals and guidelines that explain what techniques and methodologies can be used to undertake rigorous research, and there are a growing number of excellent resources that are intended to help non-governmental organisations (NGOs) and DPOs pursue 'action' or 'participatory' research, undertaken by members of the community or advocacy group directly.

Instead we focus on **what comes before and after research is done**: on when doing research can benefit DPOs; how DPOs can go about identifying who to work with to get this research done; and what to do with the research that has been generated.

This toolkit:

1 Explores when and how research can help your organisation (chapter 2);

2 Describes how to get the research process started, including collaborating with or overseeing researchers (chapter 3);

3 Gives a brief overview of different research methods (chapter 4);

4 Explains what can be done with the information once the research has been collected and analysed to ensure that it is used in the most effective and efficient ways (chapter 5); and

5 Provides brief definitions of key terms and phrases that regularly appear in research guides and manuals (Appendix A).

1 While this toolkit is designed with DPOs in mind, it is hoped that NGOs and other organisations working on behalf of people with disabilities will also find this toolkit useful.
2 United Nations, (2008), Convention on the Rights of Persons with Disabilities, Department of Social and Economic Affairs, New York www.un.org/disabilities/documents/convention/convoptprot-e.pdf

The ability to design and implement research is becoming increasingly important now that more than 130 countries have ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD).[2] DPOs are working much more closely with government and civil society, both to mainstream disability issues into international development policies and programmes and to design and implement disability-specific outreach efforts. Research plays a very important role in highlighting where governments are achieving their UNCRPD commitments and where there are still significant gaps. It is now more important than ever that DPOs gain the experience and confidence to plan and use research.

Chapter 2

Is research for us?

2.1 What is the value of research?

Research is often viewed as an area for specialists and the idea of 'doing research' frequently seems daunting. But research is really nothing more complicated than asking questions, typically focused around 'why' and 'how', collecting and analysing information (also called evidence or data) in a systematic way, and then using this information to answer a question or to help decide on a course of action.

All of us 'do research' every day. Any time you ask a group of people you know about what school might be best for your child, or go to several stores to compare prices on food, clothing or a mobile phone - even if you ask friends and co-workers where to go out for a meal, you are 'doing research'.

Carrying out research that is relevant and applicable to issues in people's everyday lives is called 'applied research'. The ability to use fact-based research as part of a coordinated campaign can help DPOs become more successful at influencing positive policy and programmatic changes and use their time, energy and resources more effectively. We will give you lots of examples of how research can be applied in this way in the next few chapters.

Example 2a: From hearsay to evidence – improving your advocacy

You may have come across a situation where disabled members of your community describe having trouble accessing a service or being turned away from a job training programme. You know about this from comments passed on informally by people who have experienced these problems. This is called 'anecdotal evidence'. Repeated stories like this indicate that there is something occurring which could be of concern to your organisation, or to people with disabilities in your community. But if you want to get the attention of officials, administrators, or the judicial system you need to present the information in a way which shows you have evidence that a number of people or groups have been affected and which provides information on how they are being affected. If you are able to undertake research, for example by carrying out a survey which shows the number of people or percentage of the population experiencing situations like this, or by documenting the different problems they face, then you have a much more powerful argument for the need for change.

Research can include the collection and analysis of existing knowledge, or the generation of new knowledge. Sometimes the data and evidence needed for answering questions already exists, but has not been brought together in a systematic or accessible way. In this case, someone from within your organisation might be able to research and compile this information or it might be possible to hire an outside researcher or research group to help pull the information together in a way you can use, perhaps by writing it up and presenting it in a new and interesting way.

In other situations, there may simply be no information available. If no one has ever collected data on the number of children with disabilities reaching secondary school in your area or if there is no information available on the number of women with disabilities in your region who are employed, then research may have to be undertaken in order to answer your questions. In some cases the information for part of what you need to know already exists, but further research needs to be done to answer your specific question or concern. So data may exist for example, on the number of women employed in your community but not what kind of jobs they hold or how much they earn compared to disabled men or non-disabled men and women.

With this more detailed original data, the issues can move from being an individual or anecdotal account to data that can provide the basis for collective responsibility and action. It can help to show governments, decision-makers and funders that improvements may need to be made at institutional levels. It can also highlight what structural changes are needed to make programmes and policies more efficient and effective and it can help in the design of specific outreach efforts. This type of research allows policy makers and service providers to set goals to work towards and enables advocacy groups to better monitor progress to ensure these goals are met.

Research on disability can also play an important role in highlighting the links between disability issues and other mainstream social, development or economic initiatives. It is critically important that disability issues are included as a mainstream issue in all policies and programmes affecting communities. Understanding how people with disabilities are affected by

social protection programmes, adult literacy initiatives, or HIV/AIDS programmes, for example, can contribute to a greater appreciation of the benefits of inclusive programme design and highlight where improvements are needed.

In communities where there has been great emphasis on improving voting rates or inclusion in micro-credit schemes, knowing how many adults with disabilities are participating in these efforts, and whether the participation rates are lower than or equal to their non-disabled peers, is important. If it can be shown that far fewer people with disabilities are able to vote, or to benefit from inclusion in economic or social programmes meant for everyone, then there is a more powerful argument for demanding change.

Many countries in fact now guarantee inclusion by law, especially those that have ratified the UNCRPD, so research can play a significant role in identifying the gaps between what is written in the law and what happens in practice.[3]

Top tip

Research can help an organisation to bring disability issues into mainstream policy and programme discussions by showing how persons with disabilities are affected by important development initiatives.

Quick summary: the value of research

Research can:

- Demonstrate to governments, decision-makers and funders that improvements need to be made at institutional levels

- Highlight what structural changes are needed to make programmes and policies more efficient and effective

- Provide policy makers and service providers with the information they need to set goals to work towards

- Help you to better monitor progress and ensure that governments are held to account for their disability rights commitments

- Highlight the links between disability issues and other mainstream social, development or economic initiatives

3 See Chapter 5 for a more in-depth discussion on how DPOs can use this research to engage decision makers and contribute to shadow reporting efforts.

2.2 Deciding when to use research

Not all questions need to be answered by research. Consider research as an option when you want to:

- Understand the size and scope of a particular issue and feel that having information or figures to back up anecdotal evidence will help improve advocacy or the design of activities. Knowing how many disabled children attend school or what barriers people with disabilities face in accessing social protection schemes, for example, might allow you to build an evidence-based advocacy campaign.

- Gain a more in-depth understanding of specific or complex issues as people experience them, such as the influence of people with disabilities within policy debates or their participation in community life. Knowing how people are affected by issues and what the root causes of a problem are can help to improve your activities by allowing you to focus on what works. campaign.

- Draw comparisons between different groups of individuals to answer a particular question. For example, whether women with disabilities access reproductive healthcare differently from non-disabled women, or whether water and sanitation programmes reach disabled people to the same degree as other members of their community. Being able to compare the situation faced by people with disabilities with their non-disabled peers can help provide more powerful advocacy messages targeted at mainstream development programmes as well as influencing the effectiveness of these interventions.

Chapter 3 Undertaking the research process

3.1 Getting started

Having made the decision that research is an activity you want to undertake, there are now some practical things to consider. It might help to refer to Figure 3a below as we discuss the research process over the following chapters. This figure illustrates how 'research' is a process not a single action or decision:

Coming up with an appropriate research question is the first, and most important thing to do. You will need to carefully consider what the focus of

Figure 3a: The research process

the research will be and set the context in which your question will sit. Identifying a research question or group of questions should involve thought and discussion. And it is usually important to start at the 'end' and work backwards – why do you want to do research on a particular question and how will you use the information you collect through the research in policy, programming or advocacy?

Developing a research question can be straightforward. You may want to know how many disabled young people in your community are receiving job training or how successful mainstreaming educational efforts have been for children with disabilities in the region. But research questions can also be more complicated. If you set out to document stigma and prejudice against people with disabilities in your community, you will probably want to know not only whether it exists, but what form it takes, what experience people with different types of impairments have had and whether there has been a change over time in response to new laws and public awareness campaigns. It is important for you to think carefully about what question or set of questions you want to ask, why this question is important and what individuals and/or groups can provide the answers you will need.[4]

After deciding on a research question, you must next consider how you are going to collect the data you will need. You can find more details about different research methods in Chapter 4: A brief introduction to research methods.

The research method you end up choosing may depend on a number of very practical considerations such as resources, time, and skills. Again, the overall approach should be influenced most strongly by considering **what you want to do with the results**. Chapter 5 will help give you some ideas on what you can do with different types of research results.

No matter what research approach is used, the most important thing to be aware of is the need for **good quality** research. In order to assess quality you have to make sure the research conforms to generally agreed standards – that is it should be: 'valid, reliable, replicable and generalisable'[5] (see box opposite). You need to be confident that the way the research is

Ensuring the quality of research

To be **valid**, research has to show that its data is based on the answers to the original research question. Ideally it will show a strong cause and effect that is relevant, not just to the people who took part in the research, but to all people who share their characteristics. The results or data should therefore be transferable from individual or small group cases to the wider community or population being studied.

Research that is **reliable** provides data which remains consistent over time and place.

Replicable means that it should be possible for any other researcher to get similar results or patterns if they carry out the research in the same way, using the same tools and methods but with a different set of people in the population being studied.

Generalisable data is information that can be applied to wider sections of the population, such as the wider community or region, with very little change. When data is being generalised the policy implications for the research should be made explicit.

4 For examples of recent applied research, see DFID Research for Development http://r4d.dfid.gov.uk/. For a good discussion of doing applied disability research, see N. Singal, 2010.
5 Sumner and Tribe, 2008: 100

carried out is appropriate and that the information you obtain is directly relevant to the issues you want to raise.

3.2 Hiring out or research in-house?

The next step is to make a decision about whether to do the research yourself as an organisation or hire other people to do it for you. Both options have benefits that we explore below. However, remember that regardless of who actually carries out the research, the ultimate decisions about the purpose and design of the research should be **yours**.

In-house research

If your organisation has some people with research experience then it is always worth considering whether you can carry out the research yourselves. You will need to make sure there are resources, skills and time to cover the whole process (including data collection, analysis and write-up) so that once you get started you can complete the project.

One of the benefits of doing the research yourselves is that you have complete control over the entire research process. You set all the questions, decide where and when the data collection will be carried out and control how the results are analysed, interpreted and used. It may also enable some of your staff and members to gain experience and skills in different research techniques and help you relate to stakeholders in new ways.

What you might need to be careful about however, is how **objective** your research is. If you don't have any outside involvement it can be harder to judge whether your thoughts, opinions and experiences are influencing the design of your research and the interpretation of the findings. The results of research can be heavily influenced by small details such as the way

Top tips

Hiring out or collaborating on a piece of research can bring benefits but there are also important things to be aware of when working with individual researchers or research organisations:

- This is **your** research so make sure you keep control over what is being studied. You can benefit from advice on how to make your research more effective, but if you start to feel that your original questions are no longer prominent or that the research is starting to look like something very different than what you want or need, do not be afraid to stop the process and take things back to where you are comfortable.

- There may be expectations from the academic institution or research group about how they want to use the research and there may be conditions attached to using academic staff. To avoid situations like this, it is best to make sure that all the expectations around ownership and distribution of the research are written into a contract or a Memorandum of Understanding (MoU) (see section 3.3 for more information).

questions are worded, or who you decide to ask questions of. It can sometimes be hard for you to spot those influences yourselves.

Hiring out research

If you don't feel confident about doing the research yourselves, then linking with others may be your best option. It is also possible that the scope and/or depth of the research is too much for you to cover yourselves and that hiring outside the organisation will give you better results. There are usually several places to choose from when hiring researchers. You are not limited to universities:

- Academics (Universities)
  - Faculty member (lecturer/reader/professor)
  - Research groups/institutes
  - Graduate student
- Independent research groups/companies
- Individual consultant researchers
- NGOs: There are some NGOs that specialise in research for development issues or specific populations such as women or people with disabilities

Linking with academics, either through individual connections or via local universities and research groups, can bring longer-term benefits to DPO staff and members. Working collaboratively on projects with a local university or research institution that has access to a wide range of technical skills and methods can help DPOs learn new techniques. Additionally, the university or research institution can gain valuable experience in working with people with disabilities, which greatly improves their knowledge around disability issues. Collaborations such as this could also help a DPO link to internationally recognised institutions, which raises the possibility of having any research you generate more widely distributed. On the other hand, academics and institutions will sometimes take longer to complete projects and consultations.

Figure 3b: In-house research versus hiring out research

In-house	Hiring out
Gives you more control over the process	A good option if you do not have the expertise yourselves
Gives staff the opportunity to gain research experience and develop new skills	Can help you learn new techniques
Can help you relate to your stakeholders in different ways	Outside involvement can help you to be more objective
Likely to be more efficient – academics and institutions may take longer to complete	Improves the research partner's awareness of disability issues
Usually less expensive	Can help you link to national and internationally recognised institutions and disseminate your findings more widely

3.3 Developing a research contract or Memorandum of Understanding

Setting the boundaries

If you have made the decision to hire out or collaborate on a piece of research it is important for you to make sure that everyone's expectations and roles are clear. The best way to do this is through the negotiation of a contract or Memorandum of Understanding (MoU) signed by both relevant parties.

Contract or MoU?

- A contract is a legally binding agreement subject to the laws of the country in which you are working or in which your organisation is based.

- A MoU is a document describing a mutual agreement between two or more organisations stating their intention to work together and outlining what the partnership will look like. It is not a legally binding document, but does represent a 'good faith' agreement between organisations.

A contract is used when you are agreeing to pay for a service (a survey or set of focus groups for example) that will be done within a specific period of time and that produces a specific 'product' such as an analysis of a body of data or a report. An MoU is used to establish a recognised relationship between institutions or organisations (not individuals) where there is no exchange of funding. It is often framed as lasting for a year or several years, after which time it can be renewed if both parties are satisfied with the relationship. An MoU can be used to set out an agreement to work collaboratively on a specific project or research endeavour. If there are specific tasks that need to be done as part of this agreed collaboration, especially if funding is involved, a contract will usually be drawn up concerning the specifics of the work to be undertaken.

Role/scope of work

Think about what you want the researcher or partner organisation to actually do for you. There are a whole range of different tasks you can ask the researcher to carry out. They can:

- undertake a literature search;

- collect the information;

- analyse it for you;

- provide you with a written report that you can use for your own work; and/or

- work with you to turn it into a policy, programme or activity.

You might also consider whether you want the researcher or partner organisation to help build your organisation's capacity to carry out research in the future. You could ask the researcher to provide your staff and members with the opportunity to learn about different methods of data collection and analysis whilst the research is happening. If so, make sure you talk about this when you negotiate the contract or MoU.

Getting the balance right

The group commissioning the research (i.e. your DPO) is in charge. You should therefore expect that researchers:

- Listen to what **you** want.

- Are **realistic** about expectations. Researchers can become enthusiastic about collecting data and may suggest things that are simply not affordable or add questions that are not relevant to the issues you want addressed.

- Design a project or programme that **answers the questions** that you are asking **within the time frame and budget** you have. If this cannot be done then the researchers should explain to you **why** and provide you with alternative options that let you decide whether it is worth continuing with the research, whether it should be scaled down, or whether to plan something else.

- Bring you back the results and interpret them to you in a way that meets your needs and expectations. Don't forget, if you want to have a role in the final interpretation of results then that has to be built into the scope of the work and the researcher needs to be ready to work with you on that analysis.

Many people find research intimidating, especially if there are a lot of statistical findings or detailed qualitative reports, and assume that it is their fault if they cannot understand the questions a researcher is asking or the results they are presenting. Some researchers will assume people have similar training to themselves and may think nothing of rolling out a column of figures or a statistical analysis that simply mystifies you.

Do not be intimidated! The truth is that many people find it hard to process information in this way, especially if the format is unfamiliar. Remember where your expertise lies and focus on what you want to get from the findings. Make sure you get a clear explanation from the researcher about what they plan to do, how they will go about doing it and why and how this will be relevant to what you need. If they can't do this then consider getting someone else.

Ownership of information

The ownership of the information that is produced by your research, called 'intellectual property', or 'IP' is an important issue to discuss with the researcher when you develop the contract or MoU. Intellectual property refers to all information generated by the research from the primary data collected in the field to the analysis and reports that are produced. Decisions about what information will be produced needs to be discussed with the researcher from the outset and included in the contract as 'deliverables'. That means specifying exactly what documentation you want to see created by the researcher. The contract should clearly state what you are expecting the researcher to produce for you and you should tie any payments to these deliverables.

Most researchers will ask if they can use the information generated through the research for publication. It is always best to discuss this at the start and to write agreed upon terms into the contract or MoU about what information can be used by the researcher and how your organisation should be credited. You can limit the use of information completely by writing into the contract that all information generated remains the intellectual property of your DPO. However, this level of restriction is usually unnecessary and may reduce the numbers of researchers willing to work with you.

If the research is being funded by an outside agency, it is important that you clarify the publication policies the agency has for such research before you finalise any contract or agreement with the researcher. For example they may have a logo or standard text for acknowledging their funding contribution that should be included in the final publication.

Top tips

- Many academic researchers will be more interested in working with you if they are able to publish some of the findings in academic journals. Most researchers, especially those connected to universities, are under pressure to publish on a regular basis. You can discuss this with your researcher whilst preparing the contract or MoU.

- One way you can keep control over your research data is for one or more members of your DPO to be included as a co-author on any publications. This will mean any research findings can be immediately linked to your organisation and anyone interested in what you are doing can contact you directly.

- No publication should ever appear concerning data collected for or about your DPO without your knowledge and permission.

3.4 Tips on funding research

Research can be expensive. It is important to avoid making too many compromises on budgets if it affects the quality of your research. But there are ways to keep costs down. For example:

- Don't assume that 'bigger is better' – you might be able to answer your questions using a small-scale, rigorous, qualitative study.

- If you are hiring out, researchers may be able to bring in graduate students or ask for student volunteers or interns to help and support the project.

- Consider applying for funding specifically to cover the cost. There are small grants available for research studies but you can also build research into other grant applications as part of a wider project.

- Make sure that the research questions are ones that you really want answered and meet your strategic objectives.

Charities, foundations, local and national government, and private donors are all potential sources of funding. Academic institutions and think tanks usually have limited funds and only fund scholars to do research, not outside non-profit groups. However, if you are working with or hiring a researcher connected to an academic institution, they may be able to apply for funding from their institution or a research council with your DPO as a partner.

3.5 Getting research up and running

Developing an action plan

Once you have identified the specific questions you want answered, have chosen your research method and decided who will carry out the research, the next step is to develop a **research protocol**. This is a detailed action plan which includes:

- All the information on the issue(s) you are addressing.
- The tools and methodology you will use.
- The population that you will include in your study.
- A timeline to track progress of activities.
- A budget for the work.

You can use the research protocol during the research process as a way to track progress.[6]

Top tip

Be realistic about what you can achieve with the resources that you have. Try not to overload your staff, members or others involved in the research process with too much work. Make sure you develop your plans in line with your available resources and within a realistic timeframe.

Developing a communications strategy

As early as possible during the research process you should be thinking about how you are going to use the results. Communications strategies help you identify who you want to influence, and how, where and with whom you are going to share the results. This should all link to what you want to achieve from your research.

One way to develop a good communications strategy is to discuss with key stakeholders what might be the most effective methods for communicating your messages. This could include written reports, community events, radio shows, or community drama for example, depending on who your target audience will be. There are also different forums for communication such as the Internet (Facebook, Twitter, websites, YouTube etc.), local NGO networks or community services like health clinics or village/district meetings.

Don't forget that your research may be of interest to others nationally and internationally. Findings from rigorous research on disability are very important; there is still a limited amount of evidence on disabled populations and the lived experiences of disabled people, especially in low- and middle-income countries. Your research findings may help provide examples for others working on similar issues or problems, locally, nationally and internationally.

Top tip

Remember to ensure that your findings are accessible to the disabled community by including options for alternative formats such as Braille, large type, audio, or simplified language etc. Consider where people with disabilities go for information and use those channels to disseminate your information. Reports should also be available in the local language to ensure you reach your target audiences.

6 For a more detailed discussion on this see: Mji G, Melling-Williams N, Chappel P, McLaren P (2009). Doing Disability Research: A Practical Guide to Disability Research in Africa.

Monitoring progress and results

A key part of the research protocol should be a plan for how you will monitor and evaluate the research process. For example: are you getting the information that you need? Are you producing all the documents that you wanted? Are the skills of your staff improving? If you ask these kinds of questions during the research process, it's possible to identify early on whether something is not working quite right, allowing you time to make adjustments.

3.6 Ethical approval and data protection

Ethical approval

Before carrying out any significant research process, you will need to make sure you get the right level of approval from your local and national authorities. If you are getting outside funding or working with researchers from a university you will normally require some kind of written permission before conducting any interviews or surveys in the community. If, for example, you want to conduct research around primary education, then you are likely to need permission from the ministry of education or the school board before you can talk with teachers, students or visit schools.

Committees that review research and provide 'ethical approval' are found widely at universities, ministries, schools and hospitals, even in communities and refugee camps. Funders often require ethical approval before agreeing to release research money, even if the funding has been approved. If an ethical approval committee is not available in your area, then you might consider working with other DPOs to establish such a committee, following established international guidelines.[7]

Above all, make sure you are familiar with the legal requirements around research before you get started and remember that obtaining ethical approval can be a lengthy process and could hold up research projects if you don't apply for approval as soon as possible. If you are not sure how to go about getting ethical approval, ask your local university or research group for advice.

In carrying out research, the DPO or the researchers undertaking it need to make sure they explain the purpose of the research and what kind of information will be asked of all those taking part. Taking time to introduce the research to people and communities before carrying out any surveys or interviews will also improve your response rate (people will be more willing to take part if they know what it's about) and the overall quality of your research.

 A 'consent form' will be needed, in which all those who are invited to participate in interviews, focus groups, surveys or other activities will be provided with information about why and by whom the study is being done, assured that they will remain anonymous and that they can terminate the interaction at any point for any reason. After being advised of these rights, participants will be asked to give their written or oral permission to proceed.[8]

7 A series of papers on research ethics and ethics committees in international development and global health are available through DFID. A good place to begin is with: DFID. Research Ethics in Developing Countries. April 2008 Number 304. www.parliament.uk/documents/post/postpn304.pdf.
Also see: ESRC Framework for Research Ethics (FRE) 2010 updated September 2012
http://www.esrc.ac.uk/_images/Framework-for-Research-Ethics_tcm8-4586.pdf
8 For more information on this see: Mji G, Melling-Williams N, Chappel P, McLaren P (2009). Doing Disability Research: A Practical Guide to Disability Research in Africa.

Anyone who has a role in collecting data from the field should have some form of identification (this can range from official badges to t-shirts and hats) and must be authorised by your organisation to carry out the work.

If you would like to use photographs of participants in subsequent publications or reports, you should always get their express permission (preferably in writing) prior to taking the photographs. It should be very clear how the photographs will be used and whether the participant agrees; for example you may want to consider excluding the exact name and location of the participant from the report in order to maintain confidentiality.

Data protection

Any information that is collected from people, during interviews or surveys for example, must be treated respectfully. People have a right for their personal details (including name, address, age, etc.) to be kept secure. That means:

- Making sure any paperwork that contains personal information is kept in a secure location (and is not freely available to anyone).

- Making sure any personal information is only used for the benefit of the research.

- The names of those interviewed or surveyed should not be included in any reports or write-ups unless you have their written permission to do so.

- Interview notes or surveys that have undergone analysis and are no longer needed for the purpose of the research should be destroyed (preferably shredded) so they cannot be accidentally seen by others.

If the evidence collected is personal, deals with sensitive issues locally or exposes serious concerns that need to be dealt with in-house between you and your constituents, your community, a funder or government agency, then you may not want to have any of the data you collect published – at least not until the issues raised have been addressed. Consider carefully before your research starts whether you think some of your findings might touch on sensitive issues. If so, then take measures at the start of the process to protect this information.

Child protection and vulnerable adults

Great care has to be taken when interviewing children and vulnerable adults. Safeguarding people you are working with is extremely important. If your study involves contact with children (usually defined as all those below the age of 18 years), then the same levels of child protection apply to researchers as to project staff. There should be no questions over the integrity of any of the researchers in dealing with children or vulnerable adults and this should be checked before anyone is approved for undertaking fieldwork.

No child should be interviewed alone and no child should be interviewed without the permission of their parents or guardians. This is also true for vulnerable adults - all individuals who participate in research should be given the opportunity to consent to taking part in the research (even if this means spending considerable time over the explanations). If they decide not to participate in the research project, their wishes must be respected.

Chapter 4

A brief introduction to research methods

In this chapter we briefly explain the main types of research. As noted at the outset of this toolkit, there are a number of good publications that explore how to go about designing, collecting and analysing research in international development issues. For this reason, we will not duplicate this body of information here in detail. Key books and articles are provided in the Reference section at the end of this toolkit if you are interested in the research process itself.

A particularly good publication to start with that explores what research in international development looks like from a disability perspective is 'Doing Disability Research: A Practical Guide to Disability Research in Africa', published in 2009 by the Secretariat of the African Decade of Persons with Disabilities (SAPD) for UKAID's UK Department for International Development (DFID).

4.1 Understanding different types of research

In relation to policy development and programme implementation, there are essentially four different types of research studies which can be used by your organisation:

• Desk study/literature review/background study

• Qualitative research

• Quantitative research

• Mixed methods (using both qualitative and quantitative)

Many people discuss desk studies, qualitative and quantitative research as though these methodologies are mutually exclusive, or with the expectation that you need to choose either one or the other. This is often not the case. Many studies use more than one and some use all of these approaches in combination. Desk studies, qualitative and quantitative studies will often complement each other. Whenever you are undertaking a research study, you should **first start with the question that you want to answer**, and how you intend to use the results, then you can choose whichever methods or combination of methods are most appropriate.

No matter what methodology or methodologies you use, all studies will also include two important final stages, which we will discuss below and also return to in Chapter 5:

• production of a final report providing analysis, review and discussion of all findings; and

• dissemination of results.

4.2 Desk study (sometimes called literature review or background study)

This is an important – and often overlooked – first step. This is a process in which the researcher will review and analyse all the available sources that may contain information on the question you seek to answer. This may include published work, unpublished reports, online information, government survey data, and UN, NGO and other national and regional data sets.

A thorough desk study should aim to collect information from as many diverse sources as possible such as academic journals, publications, government reports and websites. This should ensure you do not miss an important piece of information which may be critical to your research question. It will also mean that you do not 'reinvent the wheel' and devote time, energy and funding towards research when the information is already available.

If the information for your research already exists there is no need to set up new research processes. Instead your resources and time can be better spent in using the already available information to bring about change. In some cases, a good desk review can provide you with all the information you need to proceed with a project or advocacy campaign. In such cases, all that might need to be done is to bring together the existing information and circulate it widely. However, be careful when using information that has been collected by others, as some may be more reliable than others.

If, for example you are thinking of doing a survey on the number of disabled children receiving routine immunisations or going for check-ups at clinics in your region, make sure that organisations like UNICEF or Oxfam haven't already done a comparable study. Similarly, if you are interested in knowing the levels of poverty faced by disabled adults in your capital city, make sure your national government or the World Bank hasn't already collected this information within the last few years. Look for such data locally as well as at the national or international level. For example, district education offices are increasingly collecting data on numbers of disabled children in school.

A desk review is also useful for identifying where additional, new knowledge is needed. Often a desk review will help you to identify where the gaps are in the current knowledge base. If there is no information in the area you are interested in, then you can easily justify to partners and funders why such information is important to collect through new research. Likewise if there have been some studies undertaken but they don't provide enough information to answer your specific questions (or if the data is old), then you can often use these as a starting point from which to build your research process.

4.3 Quantitative research

Quantitative research provides you with information that is based on numbers and often presented in statistical form. To get quantitative information, data collection techniques like surveys and questionnaires are used. Censuses are another way of collecting quantitative information for a large number of people. Quantitative data might include statistics such as:

- 40% of children with disabilities in your region do not attend primary school.

- There are 3,400 people with disabilities living in your area.

- 23% of adults with disabilities in your village live below the poverty line, compared to 12% of adults overall.

Quantitative research can provide you with the numbers, scale, or distribution of the issue. Quantitative research can also enable you to evaluate differences in access to services between disabled and non-disabled people or between different groups within the disability community (for example disabled women compared with disabled men, or comparisons between different impairment groups).

Top tip

For a good introduction to the different ways of collecting quantitative data, see Diamond, I. and Jefferies, J (2000). Beginning Statistics: An Introduction for Social Scientists, London, Sage Publications.

Having quantitative data can increase your ability to argue or influence a cause especially if it is presented in a way that reinforces your main arguments. For example instead of saying to a policy maker or local business leader that "most disabled people do not have jobs", using well presented quantitative research you could say, "out of 50 businesses reviewed, only 5 employ people with disabilities".

Quantitative data can also show inequalities. For example, if the poorest 20% of a population of people with disabilities that you are researching are twice as

likely to have malaria compared to the richest 20% of the population, this has important programme and policy implications. Based on this data, you could consider designing a malarial programme that provides free bed nets to the poorest people with disabilities in your community rather than one that gives free bed nets to everyone. Such targeting would allow you to use your resources to concentrate on more people who most need the services.

The methods used in this type of research may or may not be easy to replicate and should produce the same types of results across a range of contexts. For this reason quantitative research is particularly useful for doing comparative analyses – perhaps comparing different social or ethnic groups, different regions or even the same groups over time.

Quantitative data can tell you many things and can be an effective tool for DPOs to use when presenting issues to policy makers, donor agencies, service providers and the general public. It can also be a powerful tool for requesting resources, as it can help you to identify the people most in need as well as to better monitor and evaluate when policies or interventions are making a difference.

4.4 Qualitative research

Qualitative research is a method that uses in-depth discussions with people, through techniques such as interviews and focus groups, to provide you with information on "why" and "how" questions. It can help to shed light and depth on people's experiences and choices. For example, using quantitative research methods might help you identify whether households with people with disabilities are economically poorer than those without disabilities, but it would not enable you to determine what causes these inequalities or understand where meaningful interventions could take place to reduce the poverty. Qualitative research on the same question of poverty in households with people with disabilities could provide you with information on what members of these households do to support themselves and what they think and feel about their experiences doing this.

Qualitative research is undertaken using a range of tools (for example, interviews and focus groups) that can include more open-ended questions or lines of enquiry that also allow more reflection from those being interviewed. Open questions let the respondent reflect on his or her own experiences and give their opinions in a more in-depth way. An example of an open question would be 'what was your experience of attending mainstream school like?' The data can often help to provide additional insight into the topic you are researching.

As most qualitative studies are more time-consuming to conduct than quantitative research, they usually involve smaller numbers of people, which can make generalisations to a larger population more difficult. However, the smaller group does give you the opportunity to investigate issues in much more depth, often allowing you the opportunity to go back to people to explore ideas further.

Case study

Case study 4a: Research conducted by people with disabilities

There are a growing number of cases in which disabled people themselves have been trained to undertake or collaborate with academic researchers on research that collects information in a qualitative way. Stellenbosch University in South Africa, for example, has recently been funded by SAFOD (Southern Africa Federation of the Disabled) through UKAID's Department for International Development to carry out a pilot certificate programme in which DPO staff are trained in these research techniques. An excellent YouTube video made by SAFOD documenting this programme is available at: www.youtube.com/watch?v=r8U9QjyRAcI.

Disability Rights Promotion International (drpi.research.yorku.ca) is also working on programmes to help establish an international system to monitor the human rights of people with disabilities. They work through DPOs around the world, training people with disabilities in the skills needed to coordinate and participate in disability rights monitoring.

Through methods such as focus group discussions, field observations, key informant interviews, storytelling, participatory rural appraisal and a number of other techniques, researchers can talk directly with people and hear from them, in their own words, what they are thinking and where they would like to see action taken. It is because of this that these methods tend to be much more participatory and allow the research participants to be much more actively engaged in the research process.

Qualitative research can be effective in enabling you to understand social phenomena and to identify relationships between key social, economic and policy outcomes and programmes. Focus group discussions with people with disabilities in a number of countries (both developed and developing) have explored the issue of social exclusion for example. Such discussions have uncovered complex relationships that reflect the multiple nature of discrimination observed (e.g. disability and gender, or ethnicity or age).

4.5 Mixed methods approach

As the name suggests, 'mixed methods' research combines both qualitative and quantitative methods and tools. For policy issues, this approach can be of more value because it makes use of the strengths of both types of research methods which can often complement each other very effectively.

Typically, studies that use a mixed methods approach include the following phases:

1. A background literature review to identify any existing data on the subject you're interested in, from both the qualitative and quantitative literatures.

2. An in-depth qualitative research component to build knowledge, typically combining methods using focus group discussions and interviews. The issues raised through this type of in-depth research can help you design better, more targeted survey questions, which in the end produce more meaningful survey results.

3. A quantitative study, to gather data on the size and nature of the issue.

4. A data analysis phase in which the data gathered from the literature review, the qualitative and the quantitative phases are each analysed separately and then 'merged'. In such cases, the data from the various components usually fit together and help support each other – although if the findings from the various methodologies do not support each other, the question of why they are not similar is also an important one.

Mixed methods studies have the advantage of being able to provide both statistical data, which is helpful when lobbying policy-makers, as well as more detailed, in-depth analyses of causes, issues and existing barriers to problems which can help when forming recommendations for change.

4.6 Analysis of research

No matter what type of methodology you use to collect the data, you will need to analyse it in a way that ensures that you accurately report on the results from your data. Here we raise several important points that are often not stated in discussions of research analysis. If you are looking for specifics on how to undertake analysis of data please see the reference section of this toolkit.[9]

• Research can often answer the questions you are asking, but the data doesn't always speak for itself. The data has to be interpreted in a meaningful way in order to have an impact on the target audience. This is particularly important in relation to statistical data. The person doing the analysis has to interpret the findings and this can be open to different interpretations. For example, if you find that 60% of the population you are working with feel strongly about a particular position, this can be stated as 'a slim majority' or 'a majority' – but if you state it as 'most people' you would be exaggerating the findings.

• When the findings for any study are reported, it is best to present first a 'findings' section where you tell the reader what you have found and then go on to have a section where you provide your comments or understanding of the research findings and their significance.

• Research projects can sometimes result in findings that are different from what you anticipated. Sometimes this is because there is a flaw in the research design or because of unanticipated factors. For example, you do a survey to determine the percentage of people with disabilities in your community. According to the latest WHO/World Bank estimates, you anticipate that you will find about 15% of the population is disabled.[10] However, you find that only 4% of the population reports a disability. This could be for a number of reasons, for example:

9 Particularly useful sources of information on analysis include: Bryman, A (2008), McNiff and Whitehead (2002), and Mji et al 2009.
10 World Health Organization/World Bank 2011.

- that you are not sampling a full range of households in the community;

- you are not defining disability more broadly to include people with milder forms of disability in your survey;

- because of stigma and prejudice household heads are not reporting family members with disabilities; or

- the rate of disability in your particular community may be lower than the international estimates.

Further research may be needed to clarify why you are getting the results you are. Sometimes the results you get will simply reflect the fact that the issue is different than what you anticipate. If this is the case, you must not ignore your findings, but think carefully about what they mean and rethink your assumptions (see case study 4b).

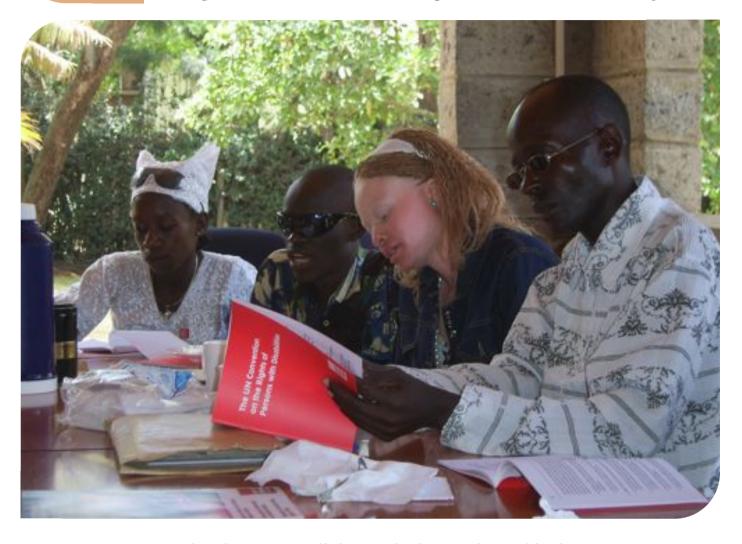## Case study

Case study 4b: Unanticipated results

Researchers working in Ecuador set out to document anticipated lower immunisation rates among children with disabilities. Weeks of travel to remote areas however found that because of successful Government and UNICEF immunisation campaigns, immunisation rates for all children were very high. Moreover because of a local positive attitude towards disability, immunisation rates among children with disabilities were equal to those for their non-disabled peers.

This research was begun with the assumption that lower rates of immunisation among disabled children would warrant a campaign to increase immunisation for children with disabilities. But after the research findings, it was clear that resources and attention for an immunisation campaign for children with disabilities would be better directed towards other disability-related issues.

Source: Groce, Ayora, Kaplan: 2007.

Chapter 5

Using research to achieve objectives and improve advocacy

In this chapter we will discuss the last (and arguably the most important) phase of most research projects – what to do with the results once they are generated. There are two related issues involved that we will cover in this chapter:

1. How your research can be used to achieve your objectives and to inform the direction of your work; and

2. How your research can contribute to your organisation's strategic objectives, future activities and programmes.

5.1 Sharing your research

Research does not disseminate itself. The last stage – and often the one most overlooked – is to make sure that the information you have generated through the research process reaches the people who need to know about

it or who could benefit by learning what you now know. It is important that the findings and recommendations generated from your research have the maximum impact upon policy makers, donor agencies, service providers and the general public.

To share your findings, it is important that you put them into a format that is usable and get them to the people and groups who would be interested. Often it is helpful for you to develop a communications strategy - indeed many people who conduct research will develop a communications strategy while they are writing up the initial research proposal (see Chapter 3, page 17).

Disseminating the results of the research is important both to show people what you have found and to add to the overall knowledge base on disability. But too often people think of research dissemination in terms of only one audience – an academic paper or a report. It is good to think about sharing your findings for different audiences on at least three levels:

a   An academic paper to share the research findings in a globally recognised format. If you are working with people who publish regularly, they can help you develop such a paper, but anyone can write and submit an academic paper and all journals have submission guidelines available online. Sharing the results of your study might be of interest to others who are doing similar research.

b   A description of your research published in a bulletin, newsletter or short summary paper, and put either in hard copy or shared over the Internet (or preferably both). This can help you to share your findings more widely with your key stakeholders. It can also bring your findings to the attention of researchers, policy and programming people and advocates in government, bilateral agencies, NGOs and DPOs both nationally and internationally.

c   Local dissemination of results is also important. Share your findings with local newspapers and magazines. Make yourself and your organisation available for interviews by local (and where appropriate, national) press, radio and TV. Ask if you can speak to local government groups, civic organisations (Rotary, Lions Clubs, school committees etc.) and contact local universities to see if they might be interested in you presenting your research findings.

A key issue in global disability research circles in recent years has been the lack of good and robust data on local issues, as well as descriptions of 'best practices' and research findings that raise new insights into disability issues within the broader context of international development and global health concerns. The research findings that your organisation generates may well find a much wider audience than you anticipate.

And don't be shy – once you have written a paper or posted a description on a website, use the Internet to share it widely with any colleagues who might be interested through open access publications and methods.

Top tip

One of the real advantages that research gives is the ability to open up dialogue with decision-makers. Awareness-raising can get an issue more prominently into the public eye, but if you want people to make changes you have to provide them with some evidence as to why change is needed.

Leonard Cheshire Disability Young Voices members meet with the Prime Minister of Sri Lanka.

5.2 Engaging decision-makers

Research can be used by DPOs to engage more directly with those in power. Even basic accessibility audits of government offices, facilities or local businesses can create the opportunity for dialogue. Larger scale research can help support governments to identify where the gaps are in their services. Many health ministries, for example, are broadly aware they are not meeting the needs of disabled children but they have little or no data on which to base any changes in health policy or practice.

Often people in decision making positions will want to see evidence of the scale, nature or scope of the problem and what you believe will make a difference. They will also want to see evidence to justify the allocation of resources specifically to disability issues when there are a number of groups with competing needs (e.g. women's groups, children's organisations, rural associations). Strong reasons have to be given as to why change is necessary. Typically, few decision makers (especially those at government level) will have knowledge or experience in disability issues and often rely on DPOs and other organisations for information. Policy makers are particularly persuaded by statistical data, as often there is a need to make an "economic case" for a change in policy and programme implementation.

5.3 Informing advocacy plans

Designing an effective campaign for change starts with **knowing what you want to change**. It is tempting to want to miss out this step and get straight down to planning activities without having first analysed what problem or issue is to be addressed.

Research is a valuable part of the advocacy process because it helps establish what the cause and effect of policies, programmes, attitudes or practices are with greater certainty. Once you have that level of background information it is then much easier to design activities which target specific changes in behaviour, policies or attitudes. Keeping advocacy focused, with simple, realistic and realisable objectives, is the key to success. Research can play a significant role in identifying a few key issues, providing a clear understanding of what success will look like.

Example 5a: Quantative research in advocacy

Imagine that from anecdotal reports, it appears a lower proportion of children with disabilities are attending school compared with their non-disabled peers. You want to convince the Ministry of Education that they must spend more time and money to get children with disabilities into school. Any campaign you design will be much more successful if you can prove – with evidence – that a higher proportion of children with disabilities than non-disabled children are out of school. The results of a quantitative survey of school age disabled and non-disabled children in your area should give you the evidence you need to reinforce your campaign messages.

Example 5b: Qualitative research in advocacy

You want to convince parents in a particular location to send their disabled children to school. Here qualitative research might prove more useful. Unlike the Ministry of Education audience you want to reach in the previous example, parents may not care about how many children are involved – their concern is for their own child. Research involving interviews with parents and educators should help you to better understand their expectations of education for children with disabilities and what additional barriers may be affecting their decisions (e.g. transport, lack of accessible toilets, bullying from non-disabled children).

The information you collect in this way will help you create a message which is locally relevant and persuasive. In this example, you need research that is valid and reliable, and which uncovers what the various barriers are to inclusion in a particular location. However, it does not have to produce conclusions which can be generalised to all children with disabilities.

5.4 Improving campaigns so they have a real chance to influence policy changes

With evidence, you have a more robust base upon which to build a powerful campaign. Research data can provide DPOs with an excellent basis from which to argue for specific policy reforms. That means taking a policy, for example an education, employment or HIV/AIDS policy, and highlighting areas where its implementation is either neglecting the needs of people with disabilities or is actually having a negative effect by excluding them. If you have strong evidence which shows that a policy in its current form is having a negative impact, or is excluding significant numbers of people with disabilities, then it can make it easier to call for a wider consultation process and review of the policy with decision makers.

Individual DPOs can also come together, either to implement larger-scale regional or national research projects, or to build on previous research carried out by other DPOs as a way to strengthen arguments.

5.5 Producing shadow reports

One of the most significant changes in disability rights in recent years has been the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This human rights framework offers huge potential for DPOs as a focus around which to campaign and lobby. Initial efforts need to be put into ensuring governments ratify the Convention. Once that has been achieved there is much to be done to support its implementation. At this stage research can become an essential tool for DPOs as a way to highlight where the UNCRPD is making positive progress or where legally mandated changes are lagging behind.

All countries that ratify the UNCRPD have to produce regular updates for the UN on how well and to what extent they are complying with the Convention. Governments will do this in a very general way since there are a lot of different areas they have to cover. Typically they will want to focus on where they have made the most progress.

However, the UN also encourages **shadow reporting** from non-governmental agencies. These can be submitted around the same time as government reports. Shadow reports provide an exciting opportunity for DPOs to highlight areas where there has been little or no progress or where the situation might not be changing in quite the way the UNCRPD intends. To be credible however, these shadow reports must be based on accurate and reliable research.

Shadow reporting need not be confined to UNCRPD-related work. In any domain in which the official records and reports do not reflect what is actually going on for people with disabilities, a shadow report by DPOs, based on accurate research, can help engage government officials, civil society and the general public in discussion and debate related to the needs and concerns of people with disabilities.

5.6 Building the capacity of DPOs as membership organisations

Research, as an activity, is a useful tool which organisations can use to meet many of their strategic aims and objectives. Whether it is carried out by the organisation or by others, the

process and the results can be used in many different ways. This is especially true in lobbying, advocacy and influencing policy change which is much more effective if it is based on locally relevant, up-to-date data. An evidence-based advocacy approach will help DPOs to be more effective at promoting and protecting the rights of people with disabilities with a greater focus on reducing barriers and tackling discrimination.

Involving your members in research – whether by participating in the research or actually conducting the research themselves – can help improve your relationship with your existing members and help you to recruit new members. Research, as an activity, can help improve the way individual DPO staff and members engage with their organisation from grassroots groups to the national level. Lots of qualitative research tools like focus group discussions, barrier analysis and interviews can be carried out by DPO members with very little training or support. At a local level this type of research can help identify some of the most common barriers: from negative attitudes and traditional beliefs towards people with disability to policies that are discriminatory in nature.

If DPO members develop a process of collecting and analysing data like this, the resulting information can be used to develop a local action plan. DPO members can decide to focus a small campaign on, for example, the problems faced by people with disabilities who are not allowed to open a bank account or own land. Your DPO can then develop some practical evidence-based suggestions for how this might be overcome. The more involved members are in the activities and research affecting their DPOs, the more effective DPOs become at recruiting and supporting new members.

5.7 Increasing the visibility of a DPO through research

Research activities can help raise the profile of DPOs, especially if the researchers are DPO staff or members themselves. Research as an activity can form part of a much wider awareness-raising programme. Before carrying out surveys or interviews for example, the study locations often need a period of sensitisation which can give DPOs an excellent opportunity to start talking to local leaders, government officials and community groups about disability. Of course, once people start going into communities and asking disability-related questions, the profile and importance of the issue grows considerably. This is even more effective if the data collection is carried out by DPO members.

5.8 Improving awareness of the social/rights perspective on disability through research

When DPOs are involved directly in research it is often a very empowering process. Many people with disabilities will come from families and communities where disability is regarded as a problem to be hidden; a stigmatised condition limiting the potential and opportunities a person has in life. Working with a DPO, whether people become members of the organisation or not, might be the first step in realising that there are many other people with disabilities who have had similar experiences. One excellent benefit of involving people with disabilities in research activities is that it helps them to understand the social or rights-based model of disability much more clearly. Once people start to gather more information about other people with disabilities they come to realise that often the problems lie not within themselves, but with the way they are treated by communities or service providers. This can generate a fundamental change in perception amongst people with disabilities which is an important step to creating successful advocacy.

5.9 Research that helps improve life for members at the local level

Research doesn't have to be something that always happens on a large scale or influences changes to national policies. It can be used as a way to mobilise DPO members, people with disabilities throughout the community and to make local level changes. Some DPOs have made use of accessibility audits, or visits to local businesses or government agencies for example, to assess how accessible their services are to disabled customers or disabled members of the community. Activities like this can be done on a town by town basis. If successful they can lead to significant local changes. These small changes however can sometimes have greater consequences as case study 5a illustrates.

Case study

Case study 5a: Improving access to elections

In Tangalle, Sri Lanka the Executive Committee of the Beliata DPO decided that something had to be done to improve the accessibility of the local election process. Local elections were coming up, and the current facilities prevented many people with disabilities from voting.

To get the evidence they needed they carried out accessibility audits on all the polling stations in the village and found that six were inaccessible. Using this evidence, they wrote to the divisional authorities, outlining why the venues were not accessible and what needed to be done to improve the situation. Local officials responded by promising 'to make resources available to ensure everyone can access the polling booths.' In this case, that meant people standing by with chairs ready to carry physically disabled people in. This was not full independent participation, but at least enabled ten DPO members to vote for the first time.

A key result of this small-scale research, however, was that the DPO gained official recognition that the local authorities were not fulfilling their obligations towards people with disabilities when it came to voting rights. This created the perfect opportunity for them to continue lobbying local authorities for fully accessible venues in all future elections.

5.10 Additional research

One sign of a successful research project is that it raises as many questions as it answers. While the results of a project might answer all your needs, don't be surprised if you are left with a new round of questions. The data that you generate, the skills and experience gained in doing research and contacts made with researchers in academia or the NGO sector as well as those established with funding agencies, may all enable you to pursue additional research in future. Think of the ability to do research as a skill that your organisation now has in its toolkit for future work.

Conclusion

Conclusion: Research checklist

This toolkit acts as a 'primer' on undertaking and using applied research, providing a brief introduction and framework for DPOs who are considering research as an activity. This final checklist lists the key considerations that you need to take into account when approaching and using results from any research project:

☑ Define your research questions – what do you want to know and why?

☑ Make sure your research is necessary – do you definitely need to carry out research to answer your questions? Has someone else already answered them for you?

☑ Choose your methodology carefully – desk study, qualitative, quantitative or a mixture of methods?

☑ Make sure that you have sufficient human and financial resources to undertake the research

☑ Decide whether to carry out the research yourselves (within the organisation) or hire out externally

☑ Make sure roles are clear – set out your expectations in a Memorandum of Understanding and/or contract

☑ Don't forget to consider intellectual property rights, ethics and data protection

☑ Plan carefully – make sure you produce a detailed action plan, research protocol, communications strategy and budget

☑ Think carefully about how you can use your research as early as possible and throughout the research process

☑ Share your research widely; make sure it reaches the people who need to know about it

Appendix A

Useful definitions

Accessibility audits	Surveys conducted to assess how accessible public spaces are to a wide range of potential users including people with mobility and sensory impairments.
Advocacy	Any process or set of activities which aims to influence changes in public policy or decisions.
Applied research	Research that is relevant and applicable to issues in people's everyday lives.
Anecdotal evidence	Information gained from talking to people informally (through general conversations) or through personal observations.
Barrier analysis	A process during which stakeholders identify what makes accessing a service or activity difficult for them. It usually focuses on environmental, institutional and attitudinal issues.
Case study	Process or record of research into the changes experienced by an individual person, group of people or situation through time.
Data	Facts and/or statistics collected for the purpose of analysis.
Data sets	A collection of related sets of information made up of different elements that can be analysed together.

Desk survey	Process in which the researcher reviews and analyses all the available sources that may contain information on their research question.
Evidence-based advocacy	Any advocacy activity which is accompanied by evidence gained from a research process.
Focus group discussion	A research method which gathers small groups of people together who share a common experience or characteristic. They can be asked a series of questions (often open-ended) to gain understanding about their views or they can be used to test findings and analysis.
Grey literature	Information that is available on any subject which has not gone through a peer-review.
Inclusive programmes (mainstreaming)	Sometimes referred to as mainstreaming, inclusive programmes are responsible for ensuring that all their activities are accessible and bring benefits to everyone. Often used in conjunction with gender (ensuring programmes bring equal benefits to men and women) and to disability (ensuring all those with any type of impairment can access the activities).
Institutional level (changes to/influence at)	Linked to policies or cultural practices of communities, organisations, or governments.
Intellectual property (IP)	Refers to anything that has been created by a human mind. It can range from inventions, literature, art, symbols, names, images to designs. In the case of research it refers to all information collected throughout the process from the

	responses to questions, to data sets, to the final products produced as a result of the findings.
Interviews	Process during which a person is asked a series of questions related to the research topic. The questions can be pre-designed and follow a set order or they can be open-ended.
Knowledge base	All the information or data that exists on the topic you are researching from both the peer reviewed and the grey literature.
Objectivity	Process which tries to eliminate bias from a study.
Open-ended questions	Questions which are designed to encourage people to answer using their own knowledge or feelings. Open-ended questions do not have set responses (e.g. Yes/No).
Open source	Freely available information. Papers or documents which can be accessed without having to pay.
Participatory action research/ Action research	'Participatory action research' or 'action research' is a methodology that includes members of a specific community or group helping or leading the research process by framing relevant questions, and/or collecting and analysing data, with an aim towards improving or addressing an issue or concern that impacts on their community. (McNiff and Whitehead 2002; Cornwall 2011).
Peer reviewed literature	Information that has been written up and published primarily for an academic journal after having undergone scrutiny by others in the same field.

Policy-makers	Those who have the power to write and enforce policies, such as elected and appointed officials.
Primary data	Any data which has been collected or observed at first-hand and has not been previously published.
Qualitative research/evidence	A form of enquiry which aims to gather an in-depth understanding of human behaviour and the reasons behind actions. It looks to identify the 'why' and 'how' questions behind decision making.
Quantitative research/evidence	Research which tries to uncover mathematical or statistical relationships between social phenomena.
Random sampling	Process which ensures everyone in a chosen sample group has an equal chance of being selected.
Research protocol	Detailed plan of action which outlines what information you will be collecting, what methods you will use, where your study will take place, who it will involve, how long it will take and what resources you require.
Rigorous research	Research which is thorough, based on evidence, is valid and reliable.
Secondary data	Any data which has already been collected by and is available from other sources.
Service providers	Institutions, organisations or people tasked by government with providing a service to the public. This might include health, education or environmental services for example.

Social phenomena	All behaviour which is influenced by or has influence over other individuals.
Study locations	The geographical area(s) in which you plan to conduct your research.
Survey	Research tool which comprises a set of pre-designed questions aimed at a target population or group. These can be filled in by the target population themselves (via the Internet or post for example) or they can be carried out by the researchers (house-to-house or stopping people at random in the street for example).
Triangulation	The process of establishing the validity of results by analysing a question from several different perspectives.

Appendix B

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