

RESEARCH WITH CHILDREN WITH DISABILITIES

Guidelines and Checklist for Good Practice

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For the National Disability Authority

Research with Children with Disabilities

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Good Practice**

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Guidelines for Good Practice and Checklist

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Background

Background

Introduction

This section provides an Executive summary of the Discussion Paper written to accompany the Guidelines and Checklist for those undertaking research with children with disabilities. It is hoped that readers will be encouraged to read the complete paper - this is intended to be but a foretaste with the aim of setting the context for the Guidelines and Checklist. Advances are being made in research and in our thinking about research all the time. This set of documents is intended to reflect concerns current at the time of publication, but its recommendations are not set in stone. Some of these concerns will endure and it is hoped that the suggestions in the documents will offer support to those dealing with them. New concerns may arise and it is hoped that the principles underlying the documents will be helpful in finding solutions which are acceptable.

Conceptualisations of childhood

These documents are set in the context of a re-evaluation of the status and role of children in society in Ireland as well as advances in the field of disability studies and in the context of the development of a rights-based approach in Irish disability policy (NDA, 2002b). Historical attitudes and presumptions about the nature of childhood have resulted in children being seen as vulnerable; legal notions often depict childhood as a period of powerlessness and irresponsibility; but it must also be recognised that there are differing cultural perspectives on childhood and dependence. Childhood and how it is understood have changed over space and time; children's rights are only gradually being recognised in Ireland since the ratification by Ireland of the United Nations Convention on the Rights of the Child. These rights include not only the rights to survival, development and protection but also basic civil rights - the right to freedom of expression, religion, conscience, association, information, physical integrity and to participation in decisions on matters of concern to them. However, participation does not necessarily equate with autonomy, nor with a lessening of parental responsibility - though this should be exercised in a manner which is consistent with the child's developing capacity.

In the area of social research, new approaches are developing which give greater emphasis to children as social and cultural actors instead of treating the child as subject. Researchers are now asked to ensure that opportunities are provided for children to speak for themselves and supports for so doing are, if necessary, specifically provided, especially where the situation involves children with disabilities. The rights of the child with disabilities need to be protected and also promoted because historically, they have lacked acknowledgement to an even greater extent than those of other children, and this has been due to a certain extent to the models of disability underlying approaches to service provision.

Models of disability

Individual and medical models of disability focus on the health status of the individual. The individual's health condition, whether it is a physical, sensory, intellectual or mental health condition or a combination of some or all of these, is seen as underlying all outcomes in terms of life situation and social experiences. This may result in people with disabilities being represented primarily in terms of what they lack rather than in terms of who they are and these models have been characterised as disempowering and as reinforcing rather than challenging social exclusion. (Good, 2003)

The British social model focuses more on society's shortcomings in making or failing to make adequate provision for people all the way along the continuum of human endowment in terms of physical and mental health and well-being. 'Disability' is defined variously as the social oppression or exclusion which results from society's treatment of people with needs outside the mainstream, rather than the form of impairment (Shakespeare and Watson, 2001). Disability is seen as a social construct which is built upon impairment but is not a necessary consequence of impairment. The focus in this model is on society and its disabling structures rather than on the person or persons with impairment. (Good, 2003) It has been suggested that the social model's central concern with the deconstruction of power dynamics that create and reinforce the experience of exclusion for disabled people raises some challenging issues for researchers wishing to engage in disability research (McCarthy, 2002).

A further development in recent years has been the generation of The International Classification of Disability, Functioning and Health (ICF). This model was developed by the WHO in consultation with disability NGOs and other experts during the 1990s. It conceptualises disability as 'a dynamic interaction between health conditions (diseases, disorders, injuries, traumas etc) and contextual factors' (WHO, 2001:8; DPI, 2003). This interaction is seen as being an experience common to all humans across their life span; the conceptualisation thus does not make exceptions of those with disabilities and it rejects the notion of the assumed norm which underpins previous understandings of disability (Good, 2003). It sees every person as having a place on the same continuum and does not make 'special cases' of those with different functioning and different support needs. The model has four dimensions - body structures and functions, environmental and personal factors with activity and participation being the measures of disability. This model attempts to combine the better elements of the medical and social models and is currently in use.

Defining disability

Attempting to define disability can lead one rapidly into a maze, but it needs to be confronted. The National Disability Authority (NDA) offers the following based on the UPIAS definition ' [Disability is] 'the disadvantage or restriction of activity caused by contemporary social and cultural organisations which take little account of people who

6 have impairments and thus exclude them from mainstream social and cultural activities' (NDA, 2002b, p.76). Impairments can be physical, sensory, mental health or intellectual and can have social or other causes or unexplained origins. Impairments have been recognised in the literature as having the potential to affect any or all aspects of functioning - physical, cognitive, emotional, psychological - depending on the circumstances and the supports available.

Recent disability research in Ireland

A review of disability-related research in Ireland 1996-2001 was published by the National Disability Authority (NDA, 2002b). The authors grouped the research projects which they identified under the thematic headings of Generic, Education, Employment and Training, Health, Income Adequacy and Transport. They drew attention to the prevalence of un-coordinated idiosyncratic studies, the paucity of studies emanating from the social model of disability and the finding that very few of the 400+ pieces of research identified reflected a rights-based approach in their methodology. There was concern about the low rate of participation of people with disabilities in the research process as distinct from acting as respondents - perhaps because many of the studies appeared to be based on the medical model, - concern in a few cases about the awareness of disability issues and terminology used and regret that so few studies used qualitative approaches or sought individual testimonies of experience and feelings.

Research with children with disabilities

The voices of children with disabilities have been largely absent from research on children with disabilities, not only in Ireland but internationally. There has been much criticism about research carried out with (or usually about) children with disabilities in terms of its aims (not often child-centred), in terms of it not being rights-based and in terms of its lack of provision for supporting participation in the research process. The poor extent of dissemination of this research is also criticised especially in the field of disability studies. Since 1996 the picture has changed somewhat especially in the U.K. There is a growing recognition that children's voices have not been listened to, especially in the field of disability studies; some research projects have addressed this issue directly in a qualitative way and more acknowledgement has also been given to the children's capacities to develop complex and multiple identities.

New approaches are being developed (empowering, emancipatory, participative) and are advocated by the NDA for research with people with disabilities (NDA, 2002a, 2002c). These models, with their emphasis on participation by people with disabilities and the development of more equal partnerships with non-disabled researchers, are seen as a response not only to the exclusion of people with disabilities from the research process up

until very recently, but as a necessary reaction to the oppression of people with disabilities in society and the systematic denial of their rights. It is seen as essential that disability research accurately reflects the perspectives of people with disabilities and remains focused on the issues of greatest importance to them. The difficulties underlying the new approaches are many and challenging and the NDA has developed a series of Guidelines for those trying to develop more equal partnerships (NDA,2000a, 2002b)

Core principles and values

Issues need solutions and the principles guiding the researcher towards solutions should be clear, familiar and accepted by all the parties concerned. The Children's Research Centre in Trinity College has proposed in its document (Notes on ethical issues in research with children, TCRC, 2002) that these principles be derived from a set of core values as follows:

- ▶ Having a commitment to the well-being of those participating or involved in the research process (*Beneficence*)
- ▶ Having a commitment to doing no harm (*Non-Maleficence*)
- ▶ Having a commitment to respect the rights of those involved including the rights of individuals to take responsibility for themselves (*Autonomy*)
- ▶ Being child-centred in its approach to research, listening to children, treating them in a fair and just manner as individuals in their own right (*Fidelity*)
- ▶ Having a commitment to inclusiveness and to facilitating the equal participation of those for whom obstacles might make it difficult without additional support (*Inclusivity*).

These are intended to guide the researcher in making decisions on issues which may arise in the course of a research project.

Ethical considerations

There has been some debate about whether research with children and with children with disabilities necessarily raises unique questions about ethics and methods. It has been proposed (Lindsay 2000) that research with children poses the same ethical questions as apply to other types of research, but that there are also concerns specific to children and young people. These focus upon informed valid consent and ways of ensuring that this is attained, but also that the child is included meaningfully in the decision-making process. In addition there is a duty to ensure that research is not carried out on children unnecessarily and that the degree of intrusion is minimised.

- 8 It is probably impossible, and it would be inadvisable, for researchers to determine alone the appropriate solutions to the dilemmas which may arise in doing research with children with disabilities. The NDA has recently issued guidelines on ethics in disability research (Good, 2005) as part of their support system, it is recommended that researchers should have access to an Advisory Group and also to an independent Ethics Committee. Research projects involving children with disabilities should in all cases have ethical approval.

Key areas in which issues may arise for researchers working with children with disabilities

Key issues are grouped in the Discussion Paper under the following headings which correspond to the main relevant components of the research process and key considerations are summarised at the end of each section.

A. Initiating the Research

- ▶ Theoretical perspectives
- ▶ Methodological principles
- ▶ Funding

B. The Participants

- ▶ Competence of participants
- ▶ Status of participants
- ▶ Access and Consent

C. The Researcher/s

D. Data Collection and Management

- ▶ General issues
- ▶ Space and time
- ▶ Confidentiality and anonymity
- ▶ Privacy and child protection
- ▶ Reliability and validity

E. Outcomes of the Research

Conclusions

Disability studies and research have made great strides since the early 1990s. Although there are many difficulties associated with research in this field, the research effort is vital and it is hoped that would-be investigators are not deterred by the magnitude of the task as it might appear from the Discussion Paper and these Guidelines and Checklist. A range of strategies has been identified which should ease their way. Forewarned is forearmed and in Ireland there is enormous potential for the development of a solid core of data which will be useful not only for the generation of policy and the assessment of practice in this country, but which will contribute to progress in the field overall. It is hoped that the range of issues and proposed solutions, as presented in the Discussion Paper and the Guidelines and Checklist will make a contribution to the thinking behind the activities which will result in that progress.

References

- Children's Research Centre Trinity College. (2002); *Notes on Ethical issues in research with children*. (Unpublished).
- Good, A. (2003); '*Competing paradigms in studying disability: the ICF as a way forward?*' Paper presented at the Annual Conference of the Sociological Association of Ireland, April 2003.
- Good, A. (2005); *Ethics in disability research*. Dublin, National Disability Authority.
- Lindsay, G. (2000); '*Researching children's perspectives: ethical issues.*' In Lewis, A. and Lindsay, G. (Eds) *Researching children's perspectives*. Buckingham: Open University Press, pp. 3-20.
- McCarthy, J. (2002); '*Beyond the Social Model: Using Emancipatory methodologies in disability research.*' (Proceedings of the Inaugural NDA Disability Research Conference. Dublin, December 2002, pp. 82-88).
- National Disability Authority (2002a); *Ask Me: guidelines for effective consultation with people with disabilities*. Dublin: National Disability Authority.
- National Disability Authority (2002b); *Disability related research in Ireland 1996-2001*. Dublin: National Disability Authority.
- National Disability Authority (2002c); *Guidelines for including people with disabilities in research*. Dublin: National Disability Authority.
- Shakespeare, T. and Watson, N (2001); '*The social model of disability: an outdated ideology?*' in Barnartt, S.N. and Altman, B.M. (Eds): *Exploring theories and expanding methodologies: where we are and where we need to go*. Research in Social Science and Disability, Vol. 2, Amsterdam, London: JAI, pp. 9 - 28.
- WHO (World Health Organisation) (2001) *International Classification of Functioning, Disability and Health*. Geneva: WHO.

Guidelines for Good Practice

Introduction

These guidelines are based on a model of childhood that sees children as active interpreters of their world with the right to be consulted on matters concerning them. The guidelines are intended for those involved in doing social research with children with disabilities and aim to inform those commissioning such research and those participating in it of best practice in the area. They have been drawn up following an extensive review of the literature and in consultation with past and potential participants in the research—children with disabilities and their parents. It is hoped that a summary of key points from the guidelines will be prepared separately for children.

The guidelines aim to be comprehensive and to suggest principles that will guide the researcher on points that may not be specifically included. They should be read in conjunction with the accompanying discussion paper on issues to be considered by those carrying out research with children with disabilities.

The principles and values underlying guidelines such as these should be clear and they should be shared and agreed by all concerned as outlined in the previous section (see also *Notes on ethical issues in research with children*, (TCRC, 2002)).

How the guidelines are organised

The guidelines are organised according to the sequence of stages that usually make up the research process, as follows:

- ▶ Planning the research
- ▶ Implementing the research design
- ▶ Analysing the data
- ▶ Disseminating the findings.

These stages and the guidelines suggested for each stage will apply whether the research project is a broadly based, epidemiological-type study using psychometric measures with a large sample or a total population, or a smaller, but equally valuable qualitative-type study. Some of the issues raised will cause difficulties and the researchers concerned will have to make decisions based on their knowledge of best practice. At each stage, specific elements of the research process will require attention and will involve making decisions. In an attempt to provide a model that is easy to remember and to implement, these elements have been identified for the purposes of these guidelines as being:

- ▶ The research activity
- ▶ The participants
- ▶ The researchers
- ▶ Information management and
- ▶ Resources.

Stage 1.

1.1 The research activity

Identify:

- ▶ The purpose of the research, e.g. exploratory, descriptive, predictive, explanatory, action; Whether it aims to be empowering, emancipatory or participative - this will have implications for the methodologies chosen;
- ▶ The nature of the research - Is it intended to be 'broad-band' epidemiological-type research about population-based topics such as health status, educational levels, general experiences, severity of disability, etc. Or is it focussed on the smaller, more detailed qualitative kind of research related possibly to personal experiences. Can the two be connected?
- ▶ The model of childhood underlying the inquiry - child as subject/object, or as a cultural and social actor and participant;
- ▶ The model of disability guiding the research medical, social, other;
- ▶ Ways in which the perspectives of children with disabilities and their parents can be included and the model of participation that might be adopted: participatory research; in steering and advisory committees; membership of consultation and planning groups; employment as researchers. (See NDA Guidelines, 2002);
- ▶ The authorship of the research question - Who is asking it and why? Is there an agenda? Does it balance positive factors against assumed problems?
- ▶ Realistic costings (see 1.5 below) - It is advisable to keep the project small scale but of high standard, rather than attempting to solve all the problems at once;
- ▶ The role of the funding agency - Is it looking for particular answers?
- ▶ Appropriate methodologies, depending on the research question - Will training be required?
- ▶ Anticipated outcomes and how they will be managed, e.g. dissemination of findings, changes in policy or practice, fostering and supporting empowerment.

Obtain:

- ▶ Peer review of the proposal from colleagues or experts;
- ▶ Ethics Committee approval before going any further;
- ▶ The support of an Advisory Group to include external experts, participants, researchers and other stakeholders, such as funders.

1.2 The possible participants

Ensure:

- ▶ Clarity and acceptability of the basis for being invited to participate in the research (e.g. age, experience, location, status, etc.);
- ▶ Inclusiveness, where appropriate (e.g. of ethnic or other minorities, children in residential care, children with differing degrees of disability, children of different ages, children not in receipt of services), depending on the purpose of the research and the population it is intended to sample;
- ▶ The development of an appropriate sampling frame - with provision for attrition if a longitudinal study is being conducted;
- ▶ The representativeness, as far as possible, of the sample selected;
- ▶ Availability of assistance/advocacy from trusted persons to potential participants from the point when the participants are first approached. These people might act as proxies;
- ▶ Availability of support (which may include transport) and help with communication, where necessary, if the potential participants are willing to become involved in the design process, as well as support in being respondents;
- ▶ Measures are put in place to ensure acceptability of proxies for the children if required and that adequate briefing of proxies has been undertaken. (Such briefing should be recorded);
- ▶ Thorough consideration of child protection issues that may arise during the conduct of the research.

1.3 The researchers

Researchers working with children with disabilities should have:

- ▶ Participated in a disability awareness programme;
- ▶ Qualifications and experience in working with children in general, and preferably also with children with disabilities, in the age group participating in the project;
- ▶ A good information base about child development;
- ▶ The ability to communicate with the specific group of participating children;
- ▶ Knowledge of physical and cognitive impairments and their likely impact on children's experiences and development at different ages;
- ▶ Knowledge of previous research findings in the area;
- ▶ An awareness of their own assumptions, biases and prejudices in relation to children in general and also in relation to children with disabilities of the age of those participating in the project;
- ▶ Knowledge of and familiarity with relevant ethical guidelines from professional organisations such as the Psychological Society of Ireland (PSI) and the Sociological Association of Ireland (SAI);
- ▶ Access to a supportive Advisory Committee and a network of professionals and experts, including representatives of children with disabilities and their parents; and in some cases, it will be helpful to set up a Reference Group of people/children with disabilities; and
- ▶ Garda clearance.

1.4 Information management

Provide:

- ▶ Details in an appropriate format, style and language (taking into account the ages and communication abilities of the children) about the purpose and nature of the research - whether it is primarily quantitative or qualitative; and about the methods, timing, possible benefits, possible harms and hoped-for outcomes of the research for potential participants, their parents, carers and gatekeepers;
- ▶ Access to alternative and augmentative modes of communication, such as sign language, Maketon, Braille, taped information, large print documentation; access to material in other languages; other communication formats and trusted people.

Arrange:

- ▶ To meet potential participants and their parents or carers in person, several times if necessary, to explain about the project, whether quantitative or qualitative, and encourage them to ask questions;
- ▶ Procedures to ensure that the children, or their parents or carers, can make contact with the researcher or a responsible person if they wish to comment on the research, ask questions or make a complaint;

Decide:

- ▶ With the participants on the ownership of the data at the end of the research project - will video/audio tapes be destroyed or stored? Who will have access to tapes? Will they be given to the participants? What is to be done about transcripts, test protocols, etc?

1.5 Resources

Costings should include provision for:

- i) training researchers/assistants in alternative ways of communication;
- ii) training researchers in appropriate methods of analysis;
- iii) payment of expenses for children, parents, carers who participate in the research; (including childcare provision, provision of assistance, and support and advocacy services);
- iv) the time needed
 - to go through the procedures and permissions necessary in many cases to access potential participants and verify the researchers' bona fides;
 - to prepare materials and inform the participants and their parents and carers before inviting their consent;
 - to build a relationship with the children (especially if the study is qualitative); and
 - to collect data from the planned number of participants, to collate, and transcribe the data, to analyse and write it up and to disseminate the findings.
- v) normal pay (salary, pension, PRSI), and non-pay related costs (insurance; transport and subsistence if travel is involved; administration; materials; telephone/fax; computers and consumables; technical assistance; assistive technology; photocopying; design and printing of materials; contingencies, etc), as well as overheads and VAT.

Stage 2.

Stage 2. Implementing the research design

2.1 The research activity

- ▶ Flexibility is a key word here in relation to methodologies, which should be piloted; and any resulting feedback should be taken into account;
- ▶ The needs and wishes of participants, as well as their age and developmental status and specific disabilities, should be ascertained and be taken into account as far as possible:
 - in selecting and adapting research methodologies (whether quantitative or qualitative);
 - in the use made of time and the decisions made regarding times for appointments;
 - in the choice of location for data collection; and
 - in arrangements made for ensuring the presence or near presence of parents or a trusted other (adult or child), regardless of whether the methodology is quantitative or qualitative;
- ▶ Comments should be invited from children and their parents or carers as the research, whether quantitative or qualitative, progresses;
- ▶ Opportunities to reflect on the research process, whatever its format, should be built in for the researchers as the research unfolds.

2.2 Participants

- ▶ Access to participants should be sought and documented, observing due procedures; with permission being sought from gatekeepers where appropriate, and respect for the rights of the individuals being observed.
- ▶ The age, life-stage, developmental status and specific disabilities of participants should be taken into consideration when inviting them to participate, whether the project is quantitative or qualitative in nature, as these factors will determine the kinds of additional support that may be required to enable them to participate at any level. If the participants are being invited to share responsibility for the research process, whether quantitative or qualitative, additional support and pre-training may be required. Support should be made available, if necessary, also after the research procedures are completed.
- ▶ Extra demands on parents/guardians/carers in situations where children with

disabilities are invited to participate in research, whether quantitative or qualitative, should be borne in mind and guarded against where possible; (for example, issues such as having to arrange transport for and to accompany a child to a particular location, leaving others with a child-minder, disrupting routines, etc.).

Informed consent

The researcher should be satisfied that the participants are adequately informed about the research, whether it is quantitative or qualitative in nature, and that they understand:

- about the purpose of the research and what is required of them,
 - about their right to refuse to consent to participate and
 - about their right to withdraw from the research at any time.
- ▶ Participants should be reminded of these rights as the research progresses;
 - ▶ Participants should be reassured that if they refuse to participate in or decide to withdraw from the research this will not be held against them in any way;
 - ▶ Parents/guardians/carers/proxies should be fully informed about the research and if they are representing children, e.g. on advisory committees, the researcher should take steps to ensure as far as possible that the views of the children are being genuinely represented. All such steps taken should be recorded;
 - ▶ Parents/guardians should be asked to consent to their child being invited to participate in the research;
 - ▶ Parents/guardians should not normally be asked to consent to participation on behalf of the child;
 - ▶ Parents/guardians should be reassured that if they refuse to participate or decide to withdraw from the research this will not be held against them in any way;
 - ▶ Consent of children should be formally recorded and witnessed.

2.3 The researchers

- ▶ The researchers should be fully informed of factors that could influence the communicative competence of the children in the study, including physical, emotional and cognitive impairments in relation to the age of the child;
- ▶ The researchers should take steps to lessen the impact of the asymmetrical relationship between them and the children and to build up a relationship of trust. This can be more problematic with children with disabilities, because the researcher has two disadvantages - being an adult and usually being non-disabled. This applies whether the research is primarily quantitative or qualitative in nature;

- ▶ The researchers should have thought through supplementary methods of helping children who are shy, or upset or have severe cognitive or communication difficulties; They may need to practise communicating with the child before undertaking the actual research, until there is agreement about mutual comprehension. It may sometimes be appropriate to invite another child to help and support the participating child. This other child must be adequately briefed and should be offered a chance to attend practice sessions. These should be recorded in the project notes;
- ▶ The researchers should devise ways of helping the children to have some control over the research process or data collection session and to practise exercising such control- for example, indicating a wish to stop. This applies both to quantitative and qualitative research approaches;
- ▶ The researcher should be careful not to raise unduly expectations of change or action for children who participate or for their parents;
- ▶ The researchers should be sensitive to the emotional needs of participants with disabilities, particularly when they have to bring the relationship to an end. This applies whether the approach has been quantitative or qualitative;
- ▶ The researchers should have measures in place to safeguard both the children and themselves from risks or allegations related to issues of Child Protection.

2.4 Information management

Confidentiality:

- ▶ Participants should be assured of the confidentiality of data collected, with the proviso that if there is any suspicion of risk to the child in the data disclosed this will have to be reported to the Health Board, normally after consultation with the child and his or her parents. If there is a fear of the child being abused before consultation is possible, there is a legal obligation to report without consultation. This should be made clear in the consent form completed for every participant;
- ▶ If data emerges that might have consequences for the services currently being availed of by the participant, these should be disclosed after appropriate consultation;
- ▶ Provision should be made for the safekeeping of data and for the ownership of data after the research project has ended;
- ▶ Any identifying information should be removed or changed. This may be particularly important when working with groups of children with specific disabilities, as they constitute quite small but heterogeneous populations;

- ▶ If working with groups, the researchers should take steps to ensure the confidentiality of matters arising in the group setting, and to ensure that the issue of confidentiality is understood by all the participants.

Feedback

- ▶ Measures should be put in place to provide motivational feedback for participants and to maintain their interest and co-operation as the research progresses, particularly if there are multiple data points. This should apply whether the research is quantitatively or qualitatively based.

2.5 Resources

Provision should be made for:

meetings with participants, gatekeepers and stakeholders to keep them up to date with the progress of the research; short written briefing reports in an appropriate format and language; sending written confirmation of appointments and thank-you letters to participants and parents; rest and refreshments if participants have had to travel and onward referral or other forms of support structures if circumstances indicate that this would be helpful to the participants or their parents/carers.

Stage 3.

Stage 3. Analysing the data

Many of the considerations related to data analysis will be common to those of research in general. These would include, for example, in relation to:

3.1 The research activity

- ▶ The maintenance of the data in a format that is efficient and accessible to the research team;
- ▶ The availability of relevant expertise and resources, for example in transcribing audio or video tapes, interpreting sign language, coding and entering data or undertaking qualitative and quantitative analysis;

In addition, when the research is being undertaken with children with disabilities, the data need to be contextualised, with more detail necessary than when other groups are the participants; context cannot be taken for granted to the same extent as it possibly could be with other groups.

3.2 The participants

- ▶ In common with research carried out with other groups, researchers should check back with participants if direct quotations are to be used - as a check for the accuracy of statements and for permission to quote participants. With children with cognitive or communicative disabilities, this process may take longer and may need more preparation and explanation;
- ▶ Where a participant refuses to be quoted or wishes to exercise editorial control, the researcher will have to omit that quotation;
- ▶ If undertaking qualitative analysis the researcher should, if possible, cross-check emerging themes with participants and their parents or guardians.

3.3 The Researchers

- ▶ Researchers should be knowledgeable about forms of data analysis that are appropriate to the data and to the research question or should have access to the relevant expertise and technology;

3.4 Information management

- ▶ The analysis should be closely linked to the original research questions;
- ▶ The whole range of evidence should be reported with balance and sensitivity, using appropriate language;
- ▶ Research with children with disabilities has in the past not focussed much on the uniqueness of individuals' stories. There is a great need for this aspect of the lives of children with disabilities to be included and highlighted where possible, even in large-scale studies. Such an approach is preferable to blending all the data into a generalised, homogenized mush;
- ▶ The findings should be related to the wider context and to theoretical standpoints; challenges to current perspectives should not be avoided;
- ▶ Appropriate arrangements should be made for the storage of data and for regulating its accessibility.

3.5 Resources

- ▶ Resources needed are similar to those for other research, except that in general, more resources are needed, and more support is required for the researchers, particularly if children with disabilities are included in the planning and execution of the research process as well as being respondents.

Stage 4.

Stage 4. Disseminating the findings

4.1 The research activity

- ▶ The findings should be related to the original research question and to the purposes of the research. They should include outcomes related to empowerment and to emancipatory and participative approaches, if these were built into the model used;
- ▶ In doing research with children with disabilities in particular, the researchers should be alert to and should report on and account for unexpected findings, whether these were quantitative or qualitative;
- ▶ The researchers should reflect on the experience of the research activity and on what was learnt from it in relation to working with children with disabilities, whether the approach was quantitative or qualitative;
- ▶ The report should include feedback on the findings from participants and a reflection on whether the research has made any difference to their lives;
- ▶ Implications for policy and practice should be spelt out, and provision should be made for informing and supporting people who need or wish to make changes to policy or practice based on the research findings.

4.2 The participants

- ▶ Participants should, where possible, have some input into the way in which the findings are presented, whether the methods used were quantitative or qualitative;
- ▶ The issue of whether findings were unexpected should be provided for in the reports presented, regardless of whether the methods used were quantitative or qualitative;
- ▶ A non-technical summary of the findings should be made available to participants/parents/guardians/carers/teachers in a suitable format;
- ▶ The participation of the children and their parents/guardians/carers/teachers should be acknowledged in the publication and, for example, their presence at the launch of any resulting report should be signalled.

4.3 The Researchers

- ▶ Depending on the nature of the research, it may be useful for the researchers to plan to meet practitioners, to talk with them about practical ways of using the research findings.

4.4 Information management and dissemination

- ▶ The findings should be reported with clarity and accuracy, minimising the risk of distortion;
- ▶ Conferences, seminars, meetings of special interest groups, including parents, other potential participants, service providers and researchers, should be organised;
- ▶ Media reports and other forms of publicity should be arranged to increase public awareness of the research and its value;
- ▶ The data obtained should be registered under the Data Protection Act.

These guidelines are intended to contribute to the quality of future initiatives in the area of research with children with disabilities. Good research depends on many factors, but the factor of concern for these guidelines is that the researchers should be familiar with best practice in the area of the project. Decisions about what constitutes best practice have to be made at various points during the course of a research project, and suggestions are made in this document that should assist the researchers in making these decisions, whether they are using quantitatively- or qualitatively-based methodologies or a combination of the two. Ultimately, the quality of the research will be underwritten by adherence to best practice; submission to peer review at periodic intervals before and during the project should help to guarantee this. Publication of a report or papers in peer-reviewed journals is a mark of the recognition of quality in research and is something that should be aspired to by all researchers.

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RESEARCH WITH CHILDREN WITH DISABILITIES

A Checklist for Good Practice

Dr. Jean Whyte

For The National Disability Authority

A Checklist for Good Practice

The model underlying this checklist sees children with disabilities as active or potentially active interpreters of their world, with the right to be consulted about matters concerning them.

The checklist should be read through completely when the research is at the initial planning stage, so that all necessary steps can be built into the research process. As the research progresses, the checklist should be re-read section by section as appropriate.

The checklist aims to be comprehensive but condensed, so that it can be followed easily. It is couched in a Yes/No format for ease of administration. It is accompanied by a draft discussion paper dealing with issues arising from research with children with disabilities and by a document containing the guidelines from which this checklist is derived.

The checklist is organised according to the sequence of stages that usually make up the research process. These stages are as follows:

- ▶ Planning the research;
- ▶ Implementing the research design;
- ▶ Analysing the data; and
- ▶ Disseminating the findings.

At each stage, specific elements of the research process will require attention and will involve making decisions; these aspects of the process have been identified for the purposes of this checklist as being the research activity, the participants, the researchers, information management and resources. These issues will require attention whether the research is broadly focused, quantitative and epidemiological in nature or is undertaken on a smaller scale using qualitative approaches.

1.1 The research activity

- ▶ Who decided on the research question?
- ▶ Was there input from children with disabilities and/or their carers?
- ▶ Is the purpose of the research to benefit children with disabilities?
- ▶ What is the anticipated outcome?
- ▶ Are the methods of investigation appropriate to the question and to the potential participants?
- ▶ Has an Advisory Group or Ethics Committee reviewed the proposal with specific regard for its ethical aspects and its approach to children with disabilities?
- ▶ Could the research do any harm to children with disabilities?

1.2 The possible participants

- ▶ Is the basis for selection for participation in the research clear and acceptable to all concerned?
- ▶ Is the basis for selection inclusive (e.g. of ethnic or other minorities)?
- ▶ In the numbers anticipated by the research design, has allowance been made for refusals and withdrawals?
- ▶ Has allowance been made in the design to provide assistance to participants to help them communicate if necessary?
- ▶ Has enough time been allowed for data collection, bearing in mind that children with disabilities may need additional support, may not have much stamina and may have ongoing needs for physical care?
- ▶ If proxies are being invited to respond on behalf of the children, have procedures been built in to brief them?
- ▶ Has consideration been given to child protection issues that may arise in the conduct of the research?

1.3 The researchers

- ▶ Have the researchers adequate preparation in relation to working with children in general and with children with disabilities in particular?
- ▶ Have the researchers prior experience of working with children with disabilities in this age group?
- ▶ Have the researchers undertaken a disabilities-awareness training programme?
- ▶ Do the researchers regard children with disabilities as capable of being mature moral agents?
- ▶ Are the researchers informed about previous research findings in the area under study?
- ▶ Are the researchers aware of their own possible assumptions, biases and prejudices in relation to people with disabilities?
- ▶ Have the researchers dealt with experiences in their own past that might impinge on their interpretation of data in this project?
- ▶ Do the researchers have a support/supervisory/advisory network?
- ▶ Do researchers who will be working alone with children have Garda clearance?

1.4 Information management

- ▶ Have potential participants, their parents, carers and gatekeepers been given details in an appropriate format and style about the purpose and nature of the research, its methods, timing, possible benefits, possible harms and hoped-for outcomes?
- ▶ Do the researchers have access to alternative and augmentative modes of communication, such as sign language, Maketon, Braille, taped information or large-print documentation; are they proficient in other languages or do they have access to resources in languages other than English; and is information available to researchers in other formats, if necessary, to inform participants?
- ▶ Have the researchers arranged to meet potential participants and their parents or carers in person, in order to explain about the project and to encourage participants or their representatives, using an interpreter if necessary, to ask questions?
- ▶ Have procedures been put in place to ensure that children, or their parents or carers, can make contact with the researcher if they wish to comment, ask questions or make complaints?

1.5 Resources

- ▶ Has the project been costed, so that provision has been made for:
 - i) training researchers/assistants in alternative ways of communication
 - ii) training researchers in various methods of analysis?
- ▶ Have sufficient resources been allowed for so that researchers have enough time to
 - a) go through the procedures and permissions that are necessary in many cases to access potential participants;
 - b) inform the participants and their parents and carers regarding the aims of the research before inviting their consent for participation;
 - c) build a relationship with the children (especially if the study is qualitative);
 - d) collect data from the planned number of participants, collate and transcribe the data, analyse and write it up and disseminate the findings?
- ▶ Is there provision for payment of expenses incurred by children, parents or carers who participate in the research (including childcare provision)?

Stage 2. Implementing the research design

2.1 The research activity

- ▶ Have the proposed methodologies been piloted for the purposes of this study?
- ▶ Have children or their carers had an opportunity to make comments on the research and how it is to be undertaken?
- ▶ Is the research, if undertaken on a one-to-one basis, being carried out in a quiet, private place?
- ▶ Can parents/carers be present during the data-collection process, or within easy reach, if the child wishes it?

2.2 Participants

- ▶ Have appropriate procedures been followed in gaining access to potential participants?
- ▶ Has the age of the participants been taken into account in implementing the research design?
- ▶ Has the developmental status of the participants been taken into account?

- ▶ Have the specific disabilities of the participants been taken into account?
- ▶ Have the pressures on parents and carers been taken into account if they are being asked to participate?

Informed consent

- ▶ Is the researcher satisfied that the participants are adequately informed and that they understand:
 - about the research and what is required of them,
 - about their right to refuse to consent and
 - about their right to withdraw at any time?
- ▶ Are participants being reminded of these rights as the research progresses?
- ▶ Have participants been reassured that if they refuse to participate in or decide to withdraw from the research this will not be held against them in any way?
- ▶ Are parents/carers/proxies fully informed about the research?
- ▶ Have parents/carers been asked to consent to their child being invited to participate?
- ▶ Have parents/carers been asked to consent to participation on behalf of the child?
- ▶ Have parents/carers been reassured that if they refuse to participate or if they decide to withdraw from the research this will not be held against them in any way?
- ▶ Has consent been formally recorded and witnessed?

2.3 The researchers

- ▶ Are the researchers fully informed of factors that could influence the communicative competence of the children in the study?
- ▶ Have the researchers taken steps to lessen the impact of the asymmetrical relationship between them and the children?
- ▶ Have the researchers thought through possible methods of winning the child's confidence and trust?
- ▶ What provision have the researchers made to help children who are shy or upset or have severe communication difficulties?
- ▶ Have the researchers devised ways of helping the children to have some control over the research process or data-collection session?
- ▶ Have the researchers put measures in place to safeguard both the children and themselves from risks or allegations related to child protection issues?

2.4 Information management

Confidentiality

- ▶ Has confidentiality of data been assured with participants and parents/carers, with the proviso that if any suspicion of risk to the child emerges in the data disclosed this would be pursued after consultation with the child?
- ▶ Has provision been made for the safekeeping of data?
- ▶ Will identifying information be removed or changed?
- ▶ If working with groups, have the researchers taken steps to ensure the confidentiality of matters arising?

Feedback

- ▶ Have measures been put in place to provide motivational feedback as the research progresses?

2.5 Resources

- ▶ Has provision been made for meetings with gatekeepers and stakeholders to keep them up to date with the progress of the research?
- ▶ Has provision been made for sending written confirmation of appointments and thank-you letters to participants?
- ▶ Has provision been made to supply rest facilities and refreshments if participants have had to travel to the research site?
- ▶ Has provision been made for onward referral if circumstances indicate that this would be helpful to the participants or their parents/carers?

Stage 3. Analysing the data

3.1 The research activity

- ▶ Have the data been maintained efficiently and in a format that is accessible to the research team?
- ▶ Has the analysis been planned around specific expertise and is that expertise available at the appropriate time?
- ▶ Have resources been put in place for activities such as transcribing tapes, coding and entering data, undertaking qualitative and quantitative analysis?

3.2 The participants

- ▶ Has provision been made to check back with participants if direct quotations are to be used – as a check on the accuracy of the data and for permission to quote participants directly?
- ▶ Have procedures been put in place to deal with a situation whereby a participant refuses to be quoted or wishes to exercise editorial control?
- ▶ If qualitative analysis is to be undertaken, have plans been made to cross-check emerging themes with participants?

3.3 The researcher

- ▶ Is the researcher experienced in appropriate forms of data analysis?
- ▶ Does the researcher have access to people with the requisite skills?

3.4 Information Management

- ▶ Is the analysis closely linked to the original research questions?
- ▶ Do the researchers report the whole range of evidence with balance?
- ▶ Can the researchers relate the findings to the wider context and to theoretical standpoints?

3.5 Resources

- ▶ Is there adequate space to store and manage the data?
- ▶ Are technological backup and data maintenance resources available?
- ▶ Is appropriate software available with which to manage and analyse data?

Stage 4. Disseminating the findings

4.1 The research activity

- ▶ Are the findings related to the original research question?
- ▶ Do the researchers report and account for unexpected findings?
- ▶ Does the report include lessons learned from the experience of the research?
- ▶ Is feedback on the findings from participants included?
- ▶ Are implications for policy and practice spelt out?

4.2 The participants

- ▶ Has a non-technical summary of the findings been made available, in a suitable format, to participants/parents/carers/teachers?
- ▶ Have the participants/parents/carers/teachers had any input into the way in which the findings are presented?
- ▶ Have they been invited to the launch of the report?
- ▶ Has their participation been acknowledged?
- ▶ Will the research make any difference to their lives?

4.3 The researchers

- ▶ Do researchers plan to meet practitioners to talk with them about practical ways of using the research findings?

4.4 Information management and dissemination

- ▶ Have the data been registered under the Data Protection Act?
- ▶ Have the findings been disseminated in academic journals and reports?
- ▶ Have conferences, seminars or meetings of special interest groups been organised?
- ▶ Have media reports and other forms of publicity been arranged to increase public awareness of the research and its findings?



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