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Stories to tell: Partnership in collaborative research

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Abstract

This paper is based on a qualitative, collaborative study, *Stories to Tell,* which explored the experiences of ten New Zealand families of children with vision impairment. The research process demonstrates a way in which the parent-professional relationship might be effected. Designed around a narrative, life history model, stories were accessed through the triangulation of focus group exploration, questionnaire and face-to-face family interviews. Excerpts from the stories, in which participants speak directly, include aspects which played a prominent part in the lives of the families. Issues relating to the education and health needs of children predominate, with educators the professionals whom parents most expect to support them. The study's families speak to other families, professionals, service providers and policy makers, and bring each the opportunity to listen, understand and integrate what is relevant to their own life experiences.

Our stories shape us. They give us our songs and our silence. When they are full of joy, they allow us to soar. When they are full of pain, they allow us to journey into the darkness of our souls where we meet ourselves, sometimes for the first time. They destroy us and allow us to rebuild. We must share our stories. They are our gifts.

(Zimmermann, 1996, p.1)

Introduction

Partnerships between parents and professionals might be expressed in a number of ways. In focusing on the future of children for whom we plan and hold hopes, Jernigan (1997) stated that "tomorrow's reality is that it is only by real partnerships that such a vision will become tangible. ... it is partnership in society as a whole where opinions are formed and blind children will learn the self image that will determine what they can do and be" (p.2). In New Zealand there is an increasing expectation by parents that partnerships reflect equality with action based on parent, as well as professional expertise. They have sought a collaborative relationship in which the knowledge and experience they bring as parents is validated and acted upon (Nagel, 1996).

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Research is one means by which the parent-professional partnership might be effected. This paper is about the partnership of ten families and a professional journeying together in research and the processes utilised. The qualitative, collaborative study, *Stories to Tell,* on which it is based blended the roles of researcher and participants to become co-researchers and co-participants. Designed around a narrative model, data was accessed through the triangulation of focus group exploration, questionnaire and face-to-face family interviews. Excerpts from the study, in which participants speak directly, include aspects which played a prominent part in the lives of the families. The study's families speak to other families, professionals, service providers and policy makers, and bring each the opportunity to listen, understand and integrate what is relevant to their own life experiences.

Collaborative research: The framework for the partnership

Collaborative research actively involves participants from the original concept through defining questions and methodologies, gathering and interpreting the data, to disseminating findings and using results (Bunning, 1995; Whyte, 1991). It can involve a variety of research approaches and methods. Turnbull and Turnbull (1991) when discussing what should constitute family research raised the issue that "all stakeholders who are affected by research should participate across a broad range of research activities" (p.9). Such research should be a collaborative endeavour based upon mutual respect, trust, potential benefits, and acceptance of each party's responsibilities. In addition it should be sensitive to cultural, social, economic, ethnic, lifestyle and lifespan dimensions. Collaborative research requires that both the researcher and the researched be open to personal transformation and raised consciousness. There is an assumption that both parties come to the research process with knowledge and experience to contribute (Maguire, 1987).

Whyte (1991) expands on the aspect of collaboration by suggesting that family members, service providers and researchers should collaborate in the research process. Knowledge fuels power and increases the efficacy of decision-making. Knowledge about persons can fuel power *over persons* or fuel power *shared with persons*. And respect for persons is shared not only in the application of knowledge about persons, but also in the generation of such knowledge (Heron, 1993).

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Thus the collaborative mode ensures that the concerns of people with disabilities, and their families, are central at every point in a research process that aims at empowerment. The model is designed to create social and individual change by altering the role relations of people involved in the process (Ward & Flynn, 1994).

The research: Stories to tell

The study, *Stories to Tell* (Nagel, 1996) was designed around a narrative, life history research model which explored the lived experiences of ten New Zealand families of children with vision impairment. It gave emphasis to interactions within families and in relation to wider social, cultural and political contexts, highlighting the impact of educational, medical and social services, and their policies on families. The stories that families told provide unique personal accounts of the meanings they received, negotiated and conveyed in relation to their lives.

There were six specific aims of the study. These were:

1. To reveal the hidden face of disability through the lives of families and whanau of children with vision impairment.

2. To explore people's lived experiences of disability in relation to such issues as attitudes, values, minority status, empowerment, disempowerment, and historical, cultural and social circumstances.

3. To identify families' coping strategies and the ways in which they have negotiated developmental tasks, information systems, service systems and support networks.

4. To identify the impact of education, health and welfare systems and policies on the experiences of families and to seek positive directions for the future.

5. To present the experiences of these families to others so that their stories might be useful to those with disabilities, their families and whanau in making a positive difference to the overall quality of their own lives.

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6.   To provide others: advocacy groups, professionals, service providers, policy makers, with the ideas, experiences and emotions of participant families as a basis for critical analysis and action for change (Lather, 1986a).
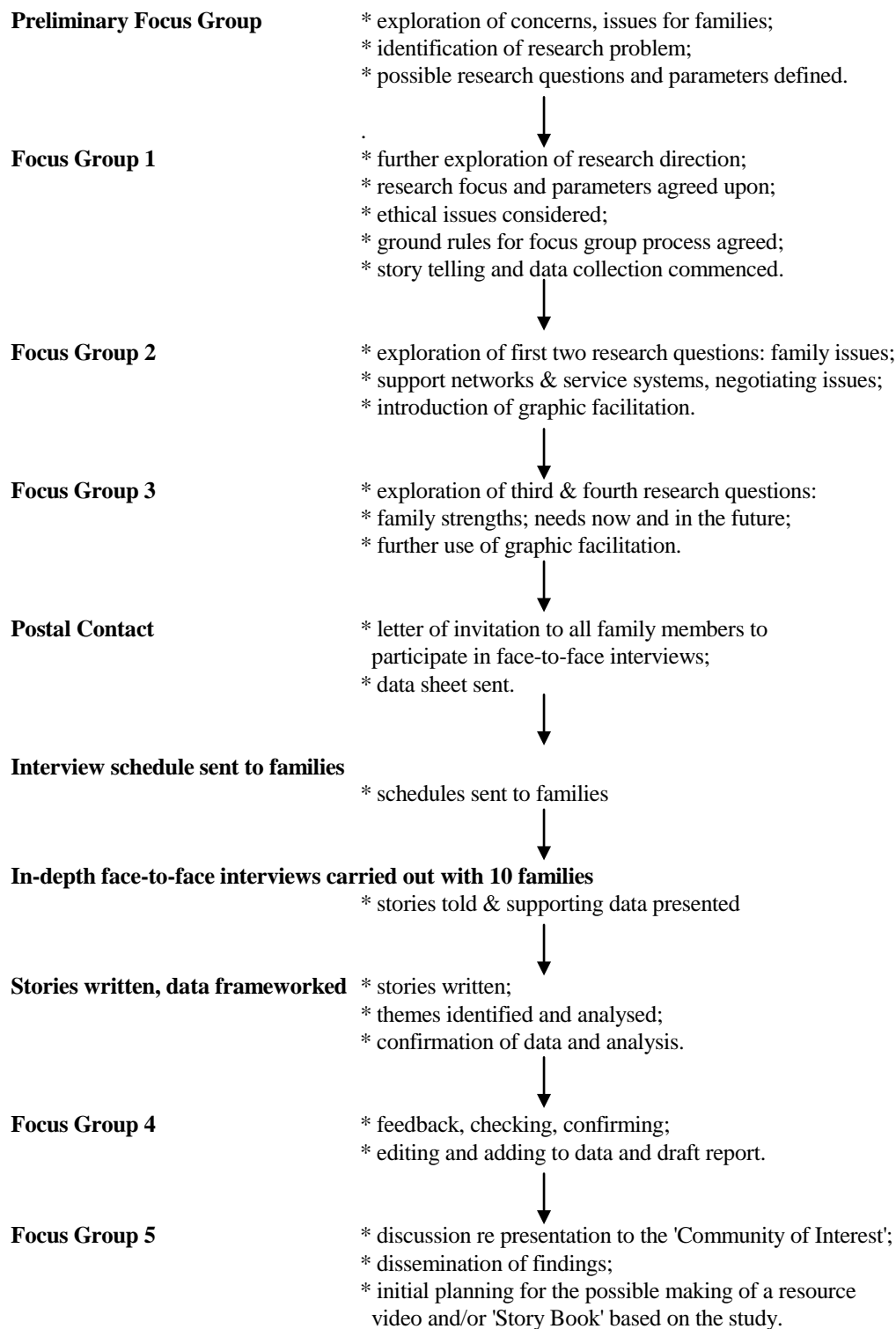

Journeying together

Co-researchers/co-participants in the study were the members of the national committee of the Parents of the Vision Impaired (PVI) organisation and their families. To reveal the stories and identify issues and themes Maguire's (1987) and Elden's (1993) framework for participatory research were followed. This comprised aspects relating to:

1.   Organisation of the study, collecting information about the area of research, analysing existing data and analysing the issues or problems faced.

2.   Defining the problem or issues experienced by both the participants and researcher.

3.   Defining the research questions.

4.   Ascertaining methods and selecting a process by which the problem can be studied.

5.   Analysing the information collected.

6.   Determining the usefulness of the findings and who might learn from them.

The focus and parameters of the study were determined collaboratively as were all aspects from the identification of the study's aims and research questions, to determining what information was presented and how it would be utilised. Stories were provided with a view to relating them as unique and personal accounts of the experiences of each family, and analysing some of the recurring issues. The richness of the stories was accessed through triangulation with supporting material, such as anecdotal writing, photographs, articles, reports and submissions also offered.

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Each process built upon, and was complementary to, those after. Figure 1, The Research Procedure, outlines the processes of the study from the preliminary focus group through to the presentation and dissemination of the research findings. In all, six focus group interviews were carried out. The first, preliminary to the study proper, was exploratory in nature and designed to seek to identify concerns and areas problematic for families which in turn led to the collaborative identification of the research problem, defining research questions and agreeing on parameters. The second, third and fourth focus groups and the family interviews focused on implementing methodology, story telling and the systematic exploration of each of the research topic areas. The final two sessions were devoted to giving feedback, validating, analysing and interpreting data, editing, reporting and making decisions about the use and dissemination of the findings.

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Figure 1   **THE RESEARCH PROCEDURE**

Preliminary Focus Group   * exploration of concerns, issues for families;
                                   * identification of research problem;
                                   * possible research questions and parameters defined.

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Focus Group 1   * further exploration of research direction;
                                   * research focus and parameters agreed upon;
                                   * ethical issues considered;
                                   * ground rules for focus group process agreed;
                                   * story telling and data collection commenced.

Focus Group 2   * exploration of first two research questions: family issues;
                                   * support networks & service systems, negotiating issues;
                                   * introduction of graphic facilitation.

Focus Group 3   * exploration of third & fourth research questions:
                                   * family strengths; needs now and in the future;
                                   * further use of graphic facilitation.

Postal Contact   * letter of invitation to all family members to
                                     participate in face-to-face interviews;
                                   * data sheet sent.

Interview schedule sent to families
                                   * schedules sent to families

In-depth face-to-face interviews carried out with 10 families
                                   * stories told & supporting data presented

Stories written, data frameworked * stories written;
                                   * themes identified and analysed;
                                   * confirmation of data and analysis.

Focus Group 4   * feedback, checking, confirming;
                                   * editing and adding to data and draft report.

Focus Group 5   * discussion re presentation to the 'Community of Interest';
                                   * dissemination of findings;
                                   * initial planning for the possible making of a resource
                                     video and/or 'Story Book' based on the study.

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The stories

The stories of the families were told with their voices heard directly. Each story is a reflection of the perspectives of the family at the particular point in time that the study was conducted. The following excerpts portray a glimpse of the stories and include aspects which play a prominent part in the lives of the families.

Expectations and a different timeframe for learning were matters raised by parents:

> In the beginning we had no idea of where Richard would be now. I didn't ever think he would ride a bike, go skiing, go to Outward Bound, swim and skateboard. Richard was twenty three when he rode a bike, so things change. I wouldn't have thought Richard would have gone on to move out of our house into a community flat. I wouldn't have thought he'd have ever adapted and yet he flourishes. (David)

> Education is probably our biggest issue. Ever since she was little, activities to do with Annie to enhance her progress, like eating and probably even playing skills and walking, we didn't really know about. I think we assumed that people have been blind forever, it's not a big deal and they cope. ... I think we just assumed that she would catch up. We didn't realise that we had to put so much effort into her achieving the normal milestones. (Sue)

Accessing information and effective communication skills featured prominently with all families:

> It's not only what you know that's important, it's what you don't know or need to find out. If you think you know everything and stop searching, stop questioning, you've lost. (Georgia)

> As people we're quite vulnerable at this stage of our life and the professionals are not perfect. A lot of them have never had any counselling skills, they've never had any people or

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communication skills. So I think that a lot of feeling centres
around the lack of communication skills and how people are
given information and how they are treated. So I see a need for
some basic counselling skills in the training of professionals.
(Rudi)

There are a lot of issues that I found as a parent I needed the
opportunity to be able to talk about - your guilt, your shame,
the whole bit - without having to continue to carry it, to be able
to say, yes, I felt guilty, and angry and the rest of it. There is a
need for someone who can find the thing that you are really
asking for in the conversation, someone with the right listening
skills. I think a person that has a good listening ear is going to
achieve more than any other person. (Violet)

Both the importance of getting others to look past their child's blindness and self-
advocacy were issues:

Dylan will be treated differently because of his blindness.
People tend to see the blindness first, rather than 'Dylan' as a
whole person.   We try to turn it around.   When I rang
Playcentre to see if Dylan could start I said, "I've got a two and
a half year old. Can I start him at Playcentre?" And then, "Oh,
he's blind", way down at the end. It's just one of those things,
like he's got brown hair. It's Dylan first. (Cushla)

The best way to ensure that Toni gets what she needs in
education and other areas of life is to bang on the desk. You
don't have a choice. If you've got a child with special needs
...you have to advocate for them or your child gets nothing.
And I know of some parents who either don't have the skills, or
don't do it for whatever reason and their kids miss out. (Alison)

Inclusive education and the attitudes of both educators and children were central to the
lives of families:

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> Our local school was just appalling in attitude.   But the
> principal of the school he attends now said to us, "Well I don't
> know actually, we've never had anyone with disabilities in our
> school but I'll talk to the teachers who would be with (him)."
> And they came back to us in a couple of days and said, "We'd
> love to try." They were just brilliant. (Theresa)

> Society's different now. Look at the schools. A lot of schools
> have got a child with some kind of a disability. ... There was
> very little opportunity for contact because people were often
> hidden away. People of our generation are not just used to it.
> But for my children when they are brought up with these
> children, they will realise that they are people in their own right
> and that they can do things. If you suddenly become a father of
> a disabled child you might think back to your schooldays and
> think, "We had Andre at our school and he was a neat kid and I
> used to love him."   That's what I think mainstreaming's
> brilliant for. (Rudi)

And, as is reflected in this paper, an honest, effective partnership in which both parent
and professional expertise was validated was of utmost significance:

> I don't trust professionals because I have found they say things
> when they don't really know the answers. I think, if anything,
> I'd like a professional to say to me "I don't know" - just to be
> open and honest about it. (Sue)

> Knowledge is power and I think some of the most wonderful
> people I have met in the professional field have been people
> who have been prepared to sit down and form that true alliance
> - not sitting there judgemental saying that you're a parent, you
> know nothing. That is absurd. ... It's about applying that
> professional knowledge to the knowledge that's gained
> practically. It's a team effort. (Cloan)

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> I think you will find we (as parents) do know what we are
> talking about. ... And you might even become demanding of
> what we know. (Raewyn)

> It's not necessarily knowledge I'm looking for, but it's just the
> acceptance and mutual understanding that we're here to work
> together - not (professionals) to make all the decisions, not me
> to just make the decisions. It's a mutual understanding of what
> needs to be done. (Georgia)

Findings

Findings from the stories were examined within the framework of Bronfenbrenner's
(1979) Ecological Model as adapted by Hornby (1994) for use with families of children
with disabilities. They were discussed in relation to their location within the four
systems of this model: microsystem (immediate family - child, mother, father, siblings);
mesosystem (extended family, peers, neighbours, friends, work colleagues); exosystem
(education, health, welfare systems, voluntary agencies); and macrosystem (ethnic,
cultural, religious, economic, political, legal systems).

Issues relating to the educational and health needs of children predominated, with
educators the professionals whom parents most expected to support them. Parents
sought parent-professional relationships which reflected equality, based on parent as
well as professional expertise. Captured in the stories they told, their various responses
depicted how professionals and their advice might be perceived by families adjusting to
life with a child with a disability, and offer, those who are professionals, the opportunity
to listen and understand this different perspective. Strategies used to negotiate both
developmental tasks and social systems were identified, with the significance of
alliances with other parents of children with disabilities highlighted. Advocacy was
deemed to be a central process in bringing about change to social systems which were
perceived as largely unchallenged by the great majority of parents.

Implications of the study are detailed in relation to families, professional practice,
service provision, policy development and future research. They underlined the
importance of a society valuing diversity, and empowerment of people disadvantaged by
prevailing attitudes, policies, structures and practices, providing a firm basis for actions
that could enhance the lives of all families of children with disabilities.

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Conclusion

The inherent value of this collaborative study lies in the uniqueness of each story and in the reader's ability to integrate meaningfully what is relevant to their own life experience.   Families were all willing to talk openly about themselves, if it would help other families to interpret and analyse their world, and to develop plans for action from new understandings. The stories present positions which recognise interests and complexity in everyday life.   They aim to raise awareness and expedite change.   As Lather (1986b) has suggested, research should contribute to a more just society.

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