Family-centred research: what does it mean and can we do it?

Over the past 20 years the idea of family-centred service (FCS) has gained currency in child health. FCS\(^1\) refers to an approach to service delivery in which families are seen as experts on their children, and professionals are encouraged to work with them in partnership to address the family’s issues. There is evidence that families’ self-reported experience of FCS is positively associated with their satisfaction with services, their mental health, and lower stress in dealing with the health care system.\(^2\)

Colleagues in a Canadian study exploring parenting of children with neurodevelopmental conditions have recently been involved in fascinating discussions about whether, and how, to engage families as partners in research. This led us to consider whether family-centred research (FCR) made sense; if so, what might it mean and how could it be undertaken? Are there potential risks as well as benefits of such an approach?

In investigator-initiated inquiry I think of health services researchers (like myself) as craftsmen who bring to the table skills in research methodology. We have the training to frame specific questions; knowledge of the rules of study design, measurement, data analysis, and interpretation; and the capacity to report the results of the studies to our colleagues. It is we who identify and explore the research questions, placing our current work in the context of what we already know, and speculating about where we think the findings of our work should lead next. Families supply the raw material – the data – with which the craftsmen work to create the research ‘product’.

However respectful researchers might try to be in the work we initiate, in this model it is we who drive the agenda. What I wonder is whether, within an FCR framework, we should strive to reconsider the direction of this process, and create research partnerships that actively build on each group’s expertise more equally from the start. In so doing it might be possible to identify and address some of the issues of power, knowledge, and privilege that make health services research an essentially professional activity. (I would distinguish what we traditionally do from Participatory Action Research, a process whereby members of the community identify the issues and engage professional researchers in a partnership to help them address their questions).\(^3\)

Examples from our recent work illustrate how much richer our studies have become with the active input of families as partners and thoughtful critics during the development of the projects. They have held us accountable for the language we use to describe them and their children. Families are extremely critical, for example, of the terminology in many of the psychosocial measures we used, which generally pathologize and emphasize problems and deficits at the expense of children’s strengths and attributes. Therefore, they asked us to provide a context for these questions, so that apparently intrusive or irrelevant items make sense to them as respondents. Families reminded us of the need to be as transparent and explicit as possible about our expectations of their commitment to the research at the consent stage, so they know what their real responsibilities will be. They field tested the measurement package and advised on the burden the study might impose. Families have also helped us to consider how best to recruit people to the study.

There are of course possible downsides to an FCR approach. Might it require a great deal of additional work to set a research agenda? Is there a likelihood that we might select a biased sample of articulate middle-class families who are ‘like us’, and in so doing actively or inadvertently miss people whose voices might clash with our values? Might researchers fear to ask questions that families might find offensive? Might families, for whatever reason, try to dissuade researchers from exploring some topics that we know to be important, or downplay findings with which they do not agree?

Some jurisdictions are well ahead on these ideas. Public and patient involvement has been mandatory in the UK for health research proposals to receive government funding. The James Lind Alliance\(^4\) is partially funded by the Medical Research Council and the Department of Health to bring patients and practitioners together to identify and prioritize important issues. Another UK-based organization, INVOLVE,\(^5\) is funded by the National Institute for Health Research (NIHR). In their own words, ‘INVOLVE works with others towards creating the research community of the future which will be broader, more inclusive and more representative of the population as a whole.’ Early evaluation of this emerging approach appears to support its value and utility across a range of benefits,\(^6\) but further exploration of the process and outcomes of FCR are clearly needed. Involving disabled children in research is one of the challenges that should also be addressed.

My colleagues and I simply wanted to raise the issues and provoke discussion of FCR as a direction to be considered, implemented, and researched – with families, of course!

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