

WHAKANUI

Elevate Learn Transform



Inclusive Evaluation and Inclusive Research Projects with Disabled People and their Whānau

“Nothing about us, without us”ⁱ

The Enabling Good Lives (EGL) principles were devised in 2011 as part of a request by the Right Honorary Dame Tariana Turia (Minister for Disability) to develop of “clean sheet” approach to community participation and day services. What eventuated was a set of working principles entitled “Enabling Good Lives” that had a much wider reach than the initial request. The Enabling Good Lives document “recommended a fundamental shift to the cross-government disability support system to give people greater choice and control over their supports and their lives” (pp1)ⁱⁱ.

The aim of EGL is about shifting authority from traditional power brokers in the disability sector to the people the sector is designed to serve, disabled people and their whānau. ‘Shifting authority’, as the name suggests, means that in all areas of support and an all work concerning disabled people they are in the drivers-seat or are working in true partnership (rather than in a tokenistic manner) with those who traditionally held the knowledge or power. Within Whaikaha: Ministry of Disabled People this means a partnership between disabled people and the Crown, and in terms of Te Tiriti o Waitangi, between disabled people, the Crown and tāngata whaikaha Māori (Māori with disability). This is a sentiment that is not new to the disability field. *People First NZ* have for years had “nothing about us, without us”, as their moto. It is quite clear what the moto means in everyday life and yet it is a moto that was largely overlooked by the sector until recently.

021 811-271

Whakanui: Elevate Learn Transform

P.O. Box 22114, Khandallah, Wellington, 6441

christinewilson.whakanui@gmail.com

Evaluation and research work with an EGL lens

There is a movement within the disability sector internationally to recognise and include disabled people into research processes, from the initial conception of a research endeavour, through the planning phases, data collection and analysis and onward toward completion and publicationⁱⁱⁱ. It is often referred to as participatory research, but variations refer also to inclusive research, collaborative research and research that is led and controlled by disabled people^{iv}. The various manifestations of this type of research challenges the traditional power base of researchers who have benefitted from an approach that excludes (sometimes quite actively) participation of their research subjects. This movement toward not only involvement and partnership, but also ownership, took its roots from research that delved into indigenous people, ethnic groups and social minorities without involving those groups in the process^v. However, it has been hotly debated in methodologies concerned with the study of disability and, more specifically, the social construction of disability. The aim of the research is to empower disabled people to take control and work toward social change on their own terms. Two dominant strands of this research are termed action research^{vi} and emancipatory research^{vii} both of which work with a presumption of participation or collaboration in the design of the research process. Later writers prefer the term 'inclusive' research as a method where disabled people not only participate but led the research process at every stage.

Inclusive research may involve disabled people who are themselves trained academics or it may involve disabled people who work in partnership as co-researchers. The value of training disabled people who are not trained academics to conduct research is important, as it will avoid the pitfalls of novice approaches but also to support and **not** destroy the creativity of unique perspectives. Inclusive approaches allow disabled people not only to set the direction of research but also the design of the methodologies themselves, which may challenge traditional approaches^{viii}. These methodologies may involve oral and visual media and traditions, role playing, conversational approaches, within group consensus (of meanings and interpretations), as well as other more traditional methods such as focus groups and hui and interviews. The work provides unique insights into the lives of disabled people and their whānau because they are made accessible to and told by disabled people and their whānau. They are not reinterpreted by researchers nor legitimised by academic reviews. They are often raw and intensely personal but individually and cumulatively they provide insight with the aim of creating positive change.

The role of research and evaluation is to tell a story. It might be a story that involves numbers and proofs commonly found in quantitative and positivist approaches to research. It might also be a story found in qualitative research and emerging qualitative methodologies. It might also be a mix of both. Numbers alone do not always give a complete understanding of a story, such as how poverty actually impacts on lives day in and day out. Likewise, the stories of those who are considered poor provide unique insights but cannot alone tell us the breadth of a particular issue. There is a role for many types of research,

but research that ignores the very people it purports to explore and report on is at best ignorant and at worst elitist.

Inclusive research can involve collaborative or partnership approaches for people or groups who find these methods fruitful. They differ from work that is wholly owned and led by disabled people inasmuch as non-disabled researchers can offer support and guidance at particular points or throughout the process. This type of partnership may well be suited to work that involves legislative bodies such as the Crown, but it becomes less effective if the partnership is not balanced in favour of disabled people being intimately involved in formulating the research questions.

If we as researchers and evaluators want to work effectively in true partnership in the disability sector, we need to embrace the ideals of EGL particularly as it pertains to self-determination, partnership (relationship building) and person-centred/directed approaches. In effect EGL shifts the authority base toward a more balanced approach.

Shifting authority creates specific tension in the disability sector as it can seem threatening to some people. However, the tension it creates has the benefit of having people sit down together and share their perspectives. From the point of view of the power brokers (those that hold the keys to funding or as some researchers view it, the 'supply side') this provides unique opportunities to hear the issues of those the system is designed to support (the 'demand side')^x. This definition (supply and demand) is of itself confronting on both sides of the equation as we are talking about people are we not? EGL has confronted this dynamic and changes in the sector are moving toward a more equitable approach through system transformation or transformation of the funding arrangement and controls traditionally associated with support^x. Central to this shift is the concept of partnership.

The traditional view of partnership is an equal balance between parties in terms of their power or influence. To build partnerships that are productive all parties need to find ways of understanding one another and the issues that are important. It requires us to build positive and progressive relationships. Finally, for the authority to shift, the person or disabled people in general (if we are looking at population-based initiatives), must be the focus (person-centred) and with true partnership that focus, drives or directs what happens next and each stage thereafter.

There are parallels in this debate with the struggle of Māori to fully realise the vision of Te Tiriti o Waitangi, especially as it relates to tino rangatiratanga (Māori sovereignty). "Rangatiratanga is first and foremost something that Māori do for themselves, by their own means and for their own purposes," (pp 439)^{xi}. The intersectional disadvantage caused by lack of adherence to Te Tiriti o Waitangi and the history of discrimination of disabled people and their whānau highlights the importance of giving tāngata whaikaha and their whānau full control over any research endeavours that concern them^{xii}. In these cases, it is the right of Māori to involve others on their own terms rather than the reverse.

How do we involve disabled people and their whānau in research?

Many of the issues facing disabled people and whānau in the modern era are related to practical social and financial problems that impact on their everyday lives. Research must be meaningful and helpful, and it must focus on the issues that disabled people and their whānau find important. Research should answer questions, show where things can work well for people, and offer suggestions of where to next^{xiii}. It should also be able to raise awareness of entrenched issues and injustices that can be presented for public debate.

Disability is a social construct. This means that people with impairments are socially disadvantaged because of attitudes and prejudices that ultimately impact on them financially, psychologically, physically and socially. They are not 'disabled' because of their impairment so much as they are 'disabled' by society^{xiv}. Attitudes about what people with learning disabilities can or cannot do are often used as an excuse to exclude or ignore their views as, at best, ill-informed and, at worst, irrelevant. Labels that place a person's intelligence at 3- or 5- or 9-year-old, immediately categorises the person as child-like and incapable. Likewise, people with physical impairments are often viewed as 'simple' and incapable. These attitudes are reinforced further if the person has mental health or behavioural needs, with the person being seen as the cause of these issues rather than their background of social disadvantage, abuse and/or their current living environments. Providing research opportunities that disabled people can take ownership of shifts the authority from those who may have harboured limiting attitudes.

The first step to involving disabled people and their whānau in research is to acknowledge and redress social constructions of disability and ensuing social attitudes and prejudices^{xv}. Mirfin-Veitch and Ballard (2005) indicate that the research led, especially if they are not disabled themselves, need to be able to identify their own bias, motives and theoretical position in any research endeavour involving disabled people. This clarity, where it is possible, lays the groundwork for developing partnership approaches^{xvi}. In many cases, the skills of the researcher can be balanced by the knowledge of people with a lived experience. Thus, skills and knowledge can be acknowledged and shared, with different stakeholders taking different responsibilities at different stages of a research project^{xvii}. With this view use of collaborative committees that comprise both professional researchers and disabled people at each stage of the research process allows the key participants to work within the research frame of reference while allowing the disabled participants to have authority over the process. The key phases of research include:

1. Discovery of research questions and areas of interest/concern that give rise to a research process. This, importantly, should be an area where the professional researcher takes the back seat. It allows the people who are the focus of the research to initiate the process.
2. Seeking funding and developing ethics statements. Often this area is conducted by the professional research team but some areas of development can be left to be completed once an application or ethical approval is granted. For example, Mirfin-Veitch and Ballard (2005) suggest writing funding approval applications in

a manner where questions of ‘how’ the research is conducted and ‘what’ is being asked can be developed further once approval granted. Ethical approvals typically will follow funding applications and a participatory or partnership approach to final research design and ethical considerations can be done by committee.

3. A collaborative approach through committees can also be undertaken to identify and source people who may be interested in being a research participant.
4. Training and supporting disabled or whānau researchers to conduct the research.
5. Involving disabled researchers and collaborative committees in the interpretation of research using a consensus approach. In this case, the process of working through qualitative materials, identification of main themes, and providing interpretations of what is being reviewed would necessitate a model whereby all of the collaborative committee members were in agreement (consensus). Likewise, using exploratory data methods for reviewing quantitative findings (such as through survey work) can also utilise a consensus approach. Projects involving positivist approaches would be more difficult for this type of research but collaborative committees can be involved at all parts of the work to this point and then be involved in the interpretation of findings.
6. Dissemination of research findings should be at the direction of disabled people in consultation (where desired) with any professional researchers who are not themselves disabled. Research findings should be able to reach the target audience and be provided in accessible formats.

This short paper represents an attempt to link the trend toward truly participatory or inclusive research with current trends toward EGL in New Zealand. The discussion is not comprehensive and raises many questions concerned with method and scientific rigor. It does, however, challenge the establishment and reminds us of ethical considerations about human participants in research endeavours. “Nothing about us without us”.

ⁱ People First New Zealand (moto) <https://www.peoplefirst.org.nz>. The term has its origins in Central European politics and became a catch phrase in the modern disability rights movement in the 1990s, being used in its present form by Charlton (2000). However, O’Brien (2020) cites a similar phrase being used by the authors of the social theory of disability in the early 1990s. O’Brien, P. (2020). “No researching about us without us as decision makers”. Commentary on “Are individuals with intellectual and developmental disabilities included in research? A review of the literature” (Jones, Ben-David and Hole, 2020). *Research and Practice in Intellectual and Developmental Disabilities*, 7(2), 120-125. Charlton, J. (2000). *Nothing about us without us: Disability Oppression and Empowerment*. University of California Press.

ⁱⁱ Cabinet Paper (2013). *Enabling Good Lives Demonstration in Christchurch*, Office of the Minister for Disability Issues.

ⁱⁱⁱ See Vollman, A.R., Anderson, E.T., and McFarlane, J. (2004). Canadian community as partner. Philadelphia PA, Lippincott Williams and Wilkins. In this work Vollman et al define participatory action-oriented research (PAR) as “a philosophical approach to research that recognizes the need for persons being studied to participate in the design and conduct of all phases (e.g. design, execution, and dissemination) of any research that affects them” pp 129.

^{iv} Jones, K E., Ben-David, S and Hole, R. (2020). Are Individuals with intellectual and developmental disabilities included in research? A review of the literature. *Research and Practice in Intellectual and Developmental Disabilities*, (7)2, 99-119. Bigby, C., Frawley, P. and Ramacharan, P. (2014). Conceptualizing inclusive

research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3-12.

^v Numans, W., van Regenmortel, T., and Schalk, R. (2019). Partnership Research: A pathway to Realize Multistakeholder Participation. *International Journal of Qualitative Methods*, 18, 1-12.

^{vi} Oliver, M. (1992). Changing the social relations of research production. *Disability Handicap and Society*, 7(2), pp 101-14; Freire, P. (1972). *Pedagogy of the Oppressed*. Harmondworth: Penguin

^{vii} Carr, W. and Kemmis, S. (1986). *Becoming critical: Education, Knowledge and Action Research*. Lewes: The Flamer Press. The distinction between action research and emancipatory research is the degree to which disabled people are in control of the process. In the latter case, the development of true partnership approaches where all parts of the research process are examined in terms of that partnership are referred to as emancipatory approaches. Conversely, action research assumes the research is devised by disabled people with the aim for social change, but the process of how the methodology is designed may create a less equitable partnership. Boyles, P (1998). *Emancipatory Research: The Potential for Change for Disabled People*, Unpublished PhD Thesis, Massey University provides an extended discussion on the requirement for a partnership approach in emancipatory research stating the need for, “defining in practice the nature of partnership before attempting to achieve the ideal of participation”, (pp 10).

^{viii} Milner, P., Conder, J. and Mirfin-Veitch, B. (2020). The aims and complexities of conducting inclusive research. Commentary on “Are individuals with intellectual and developmental disabilities included in research? A review of the literature” (Jones, Ben-David and Hole, 2020). *Research and Practice in Intellectual and Developmental Disabilities*, (7)2, 126-131.

^{ix} Numans et al (2019)

^x <https://www.health.govt.nz/our-work/disability-services/disability-projects/disability-support-system-transformation>. The Cabinet Paper on the transformation process in 2022 highlighted, “achieving better outcomes for disabled people (including disabled tamariki and rangatahi), tāngata whaikaha Māori and whānau (including parents, caregivers, and guardians) depends on transforming how government works with them. The call for “nothing about us without us” is central both to Te Tiriti o Waitangi and to New Zealand’s commitments under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and Declaration on the Rights of Indigenous Peoples (UNDRIP)” Point 4 Executive Summary

^{xi} Came, P., O’Sullivan, D. and McCreanor, T. (2020). Introducing critical Tiriti Policy Analysis through a retrospective review of the New Zealand Primary Care Strategy. *Ethnicities*, 20(3), 434-456.

^{xii} Kaiwai, H and Allport, T. (2019). *Māori with Disabilities (Part Two)*: Report Commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575).

^{xiii} Numans et al (2019)

^{xiv} Michael Oliver first referred to the social construction of disability in 1983 also see *Oliver, M. (1990). The Politics of Disablement. London: Macmillan Education.*

^{xv} Mirfin-Veitch, B. & Ballard, K. (2005). Says who? Supporting participation in disability research. In P. O’Brien & M. Sullivan (Eds.), *Allies in emancipation: Shifting from providing service to being of support*. (pp. 189-198). Palmerston North: Dunmore Press.

^{xvi} *ibid*

^{xvii} Numans et al (2019)