

family

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Abstract

Describes the work of Focus, an organisation in Canberra which supports about one hundred people with intellectual disabilities in their housing and other needs. The aim is to facilitate their involvement in the community. The organisation has been examining itself critically as a result of a visit from Michael Kendrick and this article is an attempt to share the experience of this review. **Keyword: Accommodation**

Evaluating Support: An Ongoing Review

Rob Westcott

Focus ACT Inc is an organisation based in Canberra which organises support to about 100 people who live alone or in small groups and who are generally described as having an intellectual disability. The 50 or so people employed by Focus, (mostly on a casual, ie part-time flexible hours basis) provide assistance to people with their housing and related needs. The intent is that the people who are supported live as part of the community and are viewed and treated as people. Some people have significant cognitive problems and/or have in the past been abused physically and emotionally and need lots of support; others cope better and don't need assistance so much as opportunities and acceptance. Nearly everyone has been treated badly by, or at least had mixed experiences in, the human service system. They also typically have few meaningful relationships and have had limited education. For most people their original disability is no longer their major difficulty.

Focus recently invited Michael Kendrick to lead a review team of locals and people from interstate to critically examine what was happening for people who get support via Focus and to offer some guidance. We thought it might be valuable and thought provoking to others to share our experience of our ideals and uncertainty, the review itself, and what we feel, if still with uncertainty, post review.

The Evaluation in Context

Focus used to be part of a large multi-faceted non-government organisation, the Koomarri Association, which grew out of the parent inspired movement of the 1950s. Largely as a consequence of the Disability Services Act, Focus became a separate entity in 1990 with its Board of Directors comprising a majority of people who have disabilities.

The people involved in support roles within Focus had wrestled for some time with the dilemma of how best to support people – the various trappings of residential services had been examined and re-examined: the group home model, individual supported living, Individual Program Plans (IPPs), case management, training programs, assessment processes and so on. Without being at all certain that the direction was right, this group of people had basically developed an approach of trying to support people with intellectual disabilities on an individual basis in normative ways. This meant getting to know the person as well as possible and being of assistance in a personal, kind of neighbourly, friendship oriented way. The emphasis has therefore not been on the professional-service-provision-to-consumers approach which is so popular these days. Formal assessment, programs, IPPs, files, daily reports and so on have progressively if only partly given way to lifestyle, developmental opportunities and relationship building. This is not to suggest that people are not assessed, nor provided with assistance to make plans for the future or

to learn new things. However, these aim to be individualised and oriented to the person. They are not slavishly pursued for their own sake.

Amidst this evolutionary trend, we were filled with uncertainty. After all, what is the best way, the right way to assist people who think slowly or differently or have limited understanding? How do we treat a person with respect and defend their privacy and dignity while at the same time ensuring for example that their home is clean, their health is safeguarded and their money is used judiciously and for their benefit?

To help answer these questions we sought help from Michael Kendrick who has visited other parts of Australia several times in the last few years in an advisory and educational capacity. For those who do not know him, Michael Kendrick is the Director of the Institute for Leadership and Community Development in Massachusetts, USA. Michael is a Canadian and was formerly the Director of Normalisation Training at the National Institute on Mental Retardation in Toronto, Canada. He is an associate of Professor Wolfensberger and the Training Institute for Human Service Planning, Leadership and Change Agency at Syracuse University in New York. Michael has had extensive experience working and lecturing on issues of leadership and the quality of community services and community life for persons who use those services. This has included extensive visits to, and evaluation of, services in a number of countries, extensive consultations with advocacy and consumer groups, and involvement in a wide variety of innovative projects oriented to leadership, advocacy, safeguards and improved service quality.

Choosing a person who could offer guidance of the conceptually complex nature we were seeking and who was impartial, had vision, was practical and credible, and who had spent significant time with people who had disabilities, created a dilemma in itself. There are a number of people nationally and internationally who might be identified as having such qualifications. In the final analysis there seemed three likely contenders – John O'Brien, John McKnight and Michael Kendrick. Ironically, all have contrasting views bordering on antipathy at times as to the rightness or wrongness of different ways of delivering support to devalued people though all are at the vanguard of change, all are committed to seeing people supported in the community and all support, at least in broad terms and if with varying interpretations, normalisation/social role valorisation (SRV) principles.

After some consideration it was decided to approach Michael Kendrick as it was apparent from his writings and workshops attended during several of his prior visits to Australia that he had a healthy cynicism or at least caution concerning not only traditional services but also fads. As Focus was evolving from a traditional residential service to something else that was not easily identifiable or definable and thus could be regarded as experimental or faddish, Michael seemed the most logical choice in terms of being particularly challenging. He had also lectured widely on the topic of safeguarding services to devalued people. It was certainly viewed as vital within Focus that, in the quest to improve people's quality of life through non-traditional approaches, the people in support roles didn't inadvertently diminish people's quality of life. History demonstrates this is usually what does happen – even the people who designed institutions had good intentions.

Michael accepted the invitation and the review was conducted in August, 1992. Eleven other people were recruited to form the team. Most had some experience with PASSING or other SRV related education. The team therefore comprised people with many and varied sets of experiences and perceptions.

Each team member met and spent time with a couple of people who receive assistance via Focus. Local people were able to do this over the weeks preceding Michael's visit. In all, 23 people who received support had extensive contact with team members and another 25 passing contact, ie about half the total number of people supported. Support workers, family members, workplaces and relevant others were also interviewed by team members to varying degrees. People who were known to be critical of what Focus was about (or what they perceived as being what Focus was about) were also interviewed. These included two parents, two representatives of one funding authority and three 'advocates'.

The review was challenging, even traumatic, yet enormously valuable. Many, many issues were raised and discussed and debated at length. The final report ran to some 45 pages. (If there are other people who are struggling with their personal values and how they affect support arrangements to people with intellectual disabilities, limited copies of the transcript of the review report are available on loan by contacting Focus on (06) 239 6651.)

By way of summary there were **four** primary interrelated issues which were identified by the review as already receiving yet still requiring attention within Focus. Some were perceived as potentially serious problems. Those matters are presently occupying the minds of the Board of Directors and others involved with Focus and will presumably continue to do so for some time. They are also issues on which people often have very definite opinions and they are issues which will probably dominate the debate within all human services for people with intellectual disabilities over the next few decades as they involve perception and value judgement rather than clear unambiguous fact.

1. Treating People as People or Radical Informalism Ideology?

The first issue was that of formality versus informality. There is internationally, and to a degree locally, a trend away from the rules and rigidity associated with the professional service approach and semi-institutional life. Michael described this in its extreme form as radical informalism and views it as serious a danger in human services as its opposite extreme.

Within Focus and a small number of other services, the trend toward informality has been inspired partly by the thoughts of Kendrick and more so by O'Brien and McKnight and by an increasing concern that however much we fiddle with human service models and structures, they continue to separate out people with disabilities from the rest of society while ever they exist in whatever form. They are the trappings of the service providing industry. These features have been alluded to already. They used to be things like institutions, cattle prods, restraint chairs, (and many other punitive behaviour modification techniques), IQ testing, activity therapy centres, the medical model and so on. Some of the 1990s equivalents are IPPs, the continuing, if evolutionary, artificial labelling and classification of people (into

separate and distinct groups as 'consumers'/'clients', 'service providers' and 'advocates'), case management and other 'models' of service delivery, assessment procedures and group homes (sometimes known, for example, as 'CRUs' 'staffed' by 'DD workers' who 'do PACs' and other forms of function testing on people).

The formal human service world continues to refine its policies and models ever further removed from people's fundamental need – for a home, caring relationships, personal security and self esteem and just to be treated as human beings if with the additional need of extra assistance. Informalism, practiced as an ideology that ignores or glosses over a person's disability, or that is an excuse for philosophically sound workers to do as little as possible but still get paid for it, is no better. But until there is, people who act in support roles within Focus are trying to treat people as people. We don't do it very well, not least because there are 50 part-time support people and 100 people needing support. Because society is predisposed to pushing people with disabilities into special services, there are very few other people who are prepared to share their lives on a personal basis – including many in the human service world, most frequently bureaucrats but sometimes also policy developers, 'advocates', service managers and assorted other welfare groupies who with undoubted good intentions, benefit nonetheless from the misfortune of others and the perpetuation and growth of human service systems.

None of this is to suggest that services aren't necessary. As Michael stated, until there is evidence that 'the community' supports people with disabilities better than paid service providers, services must remain. As services have mixed histories – some apparently good, some obviously awful – advocacy services need to exist to monitor their performance. However, it's already becoming apparent there is no-one to monitor the advocacy services which in the present climate can and on occasion do use innuendo and unfounded accusation against so called service providers with relative impunity. So the next step is probably to establish mechanisms which can monitor the advocacy services. And so the service cycle continues yet further removed from fundamental caring for and about people. This over organised, bureaucratised and policy dominated human service world seems in stark contrast to the notion of an ordinary, if supported life for someone who has an intellectual disability. This is succinctly described in the following statement by a person without a disability who shares his home and his life with other people who happen to have disabilities:

People ask me what's the name of your program? I smile. This isn't a program, it's our home. How would you like to live in a program: How can living be normal if what you have is a program to come home to. That is the trouble with the way many people in human services think, everything has to be a service, a model, an individualised plan, a program. That is the way bureaucrats relate to people. That's not how you care for other human beings. What they have done is substituted a hollow professionalism for what people need the most, to be loved and cared for as another human being. Services, programs, individual plans, least restrictive environment all can get in the way of understanding that one thing. (Bogdan, 1987)

In summary, Michael felt Focus was rather too eager in its pursuit of informality while also encouraging attempts at innovation and avoiding unnecessary service structures. As with anything, some balance is desirable. We will continue to struggle with the issue of formality versus informality but with a better understanding of the dangers of both.

2. Choice and Decision-making – who makes the decision to allow others to make decisions?

The second issue to occupy our minds, and no doubt many others, is that of decision-making and choice by people with intellectual disabilities. This is hardly a new issue. In 1846 Seguin said:

The typical idiot is an individual who knows nothing, thinks of nothing, wills nothing, and each idiot approaches more or less the summum of incapacity.

Seguin was an expert on 'idiots'. There are current experts on people with intellectual disabilities who equally nonsensically and at the other extreme talk of the 'differently abled' and 'people who are perceived as having an intellectual disability' as though there is no such thing as cognitive dysfunction. Most people labelled as having an intellectual disability do think remarkably clearly and have much to contribute to others as well as themselves.

But the reality is that some people to varying degrees cannot think very clearly, have limited understanding and are intellectually not very capable. This is usually exacerbated by environmental and educational deprivation in most people who have intellectual disabilities often because of human service interventions such as segregated special schools, sheltered workshops and large residential establishments.

Because people with (as distinct from people assumed to have) significant intellectual disabilities are by definition disabled to think clearly or conceptually, often on quite basic life and death matters, there is a cogent argument that other people should make choices or decisions for them. Again there is no clear right or wrong here and everyone who has an intellectual disability is different anyway. Some people, often parents and more conservative 'service providers' feel people with intellectual disabilities generally should not be allowed to exercise much choice; other people, often government policy makers and 'advocates' feel they should.

The assessment of Focus was that it pursues a 'pro-choice ideology'. Probably it does. In general – people are assumed able to make decisions and choices until proven to be unable. Obviously caution needs to be exercised with this approach, especially where people are obviously at risk but there are three reasons why the approach has seemed logical:

- Firstly, to assume people cannot make decisions or choices denies them the opportunity or at least significantly regulates and inhibits the opportunity.
- Secondly, making decisions and choices for other human beings carries with it a huge responsibility which is rarely comprehended sufficiently by those in the power role.

- Thirdly, who or what gives anyone the right to make decisions for another unless they are genuinely committed to that person, not as a paid worker providing a service to their client, but as a human being in an intimate, personal and empathic way? Within Focus we support an articulate but emotionally damaged person we know to be in a sexually abusive relationship. Do we forbid them contact or choose for that person a restraining order? We support an elderly man who has a heart condition and various other ailments. Do we forbid him his cigarettes? We support a man who has non-insulin dependent diabetes who, to a large degree, understands that no exercise, lots of sugar and not taking his medication may hasten his death. Do we make him exercise, remove his bags of sweets and, directly supervise his medication? We have not forbidden contact in the instance of the person involved in the relationship – mostly because we couldn't enforce it; we have not denied the elderly man his cigarettes but we have made the man who has diabetes exercise, we have removed his sweets and we directly supervise his medication. Thus some choices we, in our position of power, allow, while others we impose. Who makes the judgement of right and wrong and when to allow and not to allow choice and what gives us the right to make such judgements anyway? All we can say is that we endeavour to assist people with choice and decision-making from a position of caring and personally identifying with the person; not from a position as a case manager who, even if imbued with caring, views their relationship with their client/consumer as purely professional and objective.

3. Relationships – professional or personal or don't worry, programs are more important anyway?

This nature of the relationship between people who give and those who receive support is the third issue highlighted during the review. The professional distancing and de-personalising of relationships between people, one labelled 'consumer' and the other 'service provider', had been a source of much debate within Focus for some time. The re-labelling of people with intellectual disabilities from 'patients' or 'retards' to 'consumers' or 'clients' and the defining of other people as 'service providers' and 'advocates' has been just one frustration. Even more absurd are the notions that if you are a service provider you cannot advocate for people, or if you are a professional advocate, you are not providing a service. There are also varying perceptions as to whether if you are paid you can be friends with, or at least a helpful acquaintance, to the person you are assisting.

People who are involved with Focus have, to varying degrees, generally developed the opinion that being a professional has knobs on it. Yes, people who provide support get paid, they sometimes need some special skills and they need not to be exploited by their employer. People needing support don't, however, need lots of professional staff who are full of training and technique, intent on their career path and regulated by trade unions that control their work hours without also allowing for the impact on the people being supported. Nor do they need tools like WISCs, AFIs, GSPs, IPPs, CRUs, POs or TOs to live an ordinary – or close to ordinary – life. People who have intellectual disabilities usually lack meaningful relationships. We,

as non-disabled people, don't like being assessed and being programmed and cope without it. We don't cope with loneliness, rejection, and not having people close to us.

How relationships are offered to people who get support via Focus is the most vexing issue. People are not employed to be friends but they are employed among other things to facilitate meaningful, long term, non-patronising relationships between those who receive support and valued people – assuming there is time left after coping with day to day issues or helping people to maintain or learn new skills. If a friendship, however one defines it, or other form of positive relationship develops between support 'worker' and supported person in the interim that is usually considered to be great. That is not to say that all relationships are good or that people don't abuse trust, or have conflicts of interest or cause sorrow because they leave Focus. But acting humanly seems better than the alternative.

As identified by the review, Focus places too much emphasis on, as described by critics, this 'ideology at the expense of implementation strategies'. This misses the point. Treating people as people is a human function, not ideology. This then is the third issue requiring further thought and will be pondered for some time to come. Certainly we have not been particularly successful in helping people we support forge relationships with valued people despite the intention – nor for want of trying. Perhaps a partial answer for us is learning more about the experiences of Joshua Committees in North America, some of the L'Arche communities and just sharing ideas with others. If anyone reading this has had positive experiences in relationship building which is not at the expense of people's other developmental needs, we would appreciate your help.

4. Direction Setting – who is the least fallible?

The fourth key point to arise from the review concerned the setting of direction for Focus. This arose from the fact that Focus as an agency was only two years old and was very much feeling its way. This uncertainty in direction was compounded by having an inexperienced Board and one which involved people with intellectual disabilities. It was thus apparent that senior staff in effect set much of the direction of Focus or at least refined the direction that was already in place prior to the separation from its parent organisation. This created unease in many minds – certainly the senior staff and for different quite legitimate reasons some people from outside the agency who perhaps in their frustration tended to address this and related matters with, as Michael described it, innuendo rather than discussion and cooperative effort.

There is no disagreement in any quarter that Focus needs to improve the effectiveness of its Board and have it setting more directions than it is presently. A current debate is whether to remove people with intellectual disabilities from the Board (and replace them with more parents and 'experienced' Board members) and seek their contribution via advisory committees, or empower people sufficiently to contribute more effectively at Board level. The pros and cons have been heard many times before in many other services. On the one hand are arguments that people with intellectual disabilities cannot make informed decisions of the import and magnitude required of a Board (and by the law); parents must have more input; experienced

Board members bring special skills and enable the Board to give direction and manage the affairs of the organisation. On the other is the argument that involvement by appropriately skilled people with intellectual disabilities on a Board will ensure it is more attuned to people's needs than traditional Boards which are usually controlled by people who have limited contact with people with disabilities and who typically make many ill informed decisions anyway. Also parents have a uniquely valuable contribution to make but other qualifications are highly desirable as well. Most people would concur that Boards of Directors in the human service field cannot, by meeting monthly, know the subtleties and nuances that affect people's lives. Where Boards have directed service provision without the information that only comes with day to day involvement, harm is caused. Westpac is not unique. The argument in favour of 'experienced' Board members can be countered by the fact that 'experience' usually comes from traditional thinking and set ideas rather than innovation. Finally, seeking input from people with intellectual disabilities through Advisory Committees is yet more tokenism and disempowerment – and who has the right to refuse them membership of a Board in any case?

At present the Focus Board addresses two to three 'policy' issues per meeting. This is aided by a support meeting the day before involving only those board members with disabilities plus independent support people. An Executive Committee meets separately also and has limited powers delegated to it to address financial, legal and corporate matters. These arrangements are far from perfect though they are vastly better than two years ago. The dilemma now facing the Board is whether to restructure completely or to try and hasten the process of getting better at performing its function whatever that is determined to be.

There were many other matters discussed and analysed during Michael's visit. For example, the very nature of what Focus was endeavouring to achieve created conflict with a few outsiders, some of whom had very firm ideas on what was right. Focus management was not helpful on occasion by fuelling the conflict, partly through frustration and partly through guilt when mistakes were made or not enough was being achieved. This conflict has mostly subsided largely because of the review pointing out the obvious – that conflict is sometimes necessary but rarely helpful.

Focus must also consider its tendency to over rely on young support people and try to involve other people as well. There is also the need to facilitate the development and understanding of support people more (particularly about the nature of service and personal assistance to people with intellectual disabilities and the inherent contradictions), and address the image Focus sometimes projects as always being right, when ironically we are full of uncertainties. The review also pointed thankfully to a range of positives including that everyone employed, including so called management and administrative staff, spends time in support roles when in many other services increasingly such positions are created far from any direct contact with the people who need assistance.

The review was therefore of great value, if not in solving dilemmas or offering answers but in encouraging debate and consciousness about the impact of our actions and beliefs on people's lives. We encourage other agencies to undergo the

experience. We're immensely grateful to Michael and the team who worked hard and diligently on pointing out our deficits and sounding warnings in constructive ways.

Finally, if there is one fundamental belief that was confirmed by the review it is that apart from applying basic human rights and social justice principles, the 'right' way to support people with intellectual disabilities is mostly a matter of consciousness, conscience and judgement rather than any particular ideology.

Reference

Bogdan, R. (1987) *This isn't a Program, This is our home – Reflections on the over professionalised approach to care giving*. New York: Centre on Human Policy – Syracuse University.

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