Three Voices: A Case Study in Enhancing Consumer Involvement
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Abstract
The relationship between consumer’s with an intellectual disability and their service provider is a complex one. Differences between service providers and consumers in levels of knowledge, skills, power and responsibility means there is an ever present risk of disempowerment for the consumer with an intellectual disability. While there is a current trend towards service delivery which is person-centred, until late last century disability service models often created relationships based on the dependency and disempowerment of consumers. It has only been through purposeful reflection that service providers have begun to reverse this disempowerment when working with people with an intellectual disability.

While the twenty-first century has seen a shift towards consumer involvement in all aspects of service provision from planning, to implementation and evaluation: What have we learned? There appears to be a shortage of practice-based research to assist service providers to maximise positive outcomes and also deal effectively with the challenges of increased consumer involvement.

This paper provides a practice based reflection on a program to increase service user involvement in a small non-profit recreation service for people with an intellectual disability. Written collaboratively by service users, staff, management and project consultant, it aims to highlight the real practice challenges and achievements in the setting up of a service user council.
**Introducing Co-production: More than Enhancing Consumer Involvement**

Social policy trends in the last twenty years have been increasingly moving towards models of service provision which moves service users from being passive clients of pre-defined service provision to active participants defining their needs and designing their own services. Service providers are increasingly being encouraged through funding, monitoring and accreditation processes, to enhance consumer involvement. The ideal model being promulgated is one of full ‘partnership’ between service provider and service user. One which extends involvement in individual decision making towards key roles in strategic service provision at an organisational level (Beresford, September 2007; Fyson, McBride, & Myers, 2004).

The social services sector has long been working towards service provision which is client or ‘person centred’ and there are many cases where this person centeredness has moved significantly towards full partnership (Beadle-Brown, 2006; Bradshaw, 2008; Cambridge & Carnaby, 2005; Dukes, 2009; Dukes & Sweeney, 2009; Fyson, et al., 2004; Mordey & Crutchfield, 2004; Wigham, 2008).

However when working with people with reduced intellectual or decision making capacity this move towards partnership comes with a significant set of challenges, risks and associated duty of care. A set of challenges which has previously seen them excluded from many aspects of self determination (Schalock et al., 2002).

One model of practice which appears to have a pragmatic approach for service users and developers is known as co-production. Hunter and Ritchie (2007) define co-production as the partnership which occurs at an individual level “between people who use services and people who provide them”. They posit that while much research has been published on partnership at a representative governance level (for example where consumers are consulted on a board of management) the individual service provision level of partnership – one where there is likely to be most impact on individuals - requires a particular set of skills and knowledge if social services are to be innovative enough to be successful in co-production. It is also seen to raise sets of challenges for service users, staff and management alike (Mordey & Crutchfield, 2004).

This paper will provide an honest reflection on the beginning work of one small non-profit organisation providing recreation services for people with intellectual disabilities (PWID) in the setting up of a council of service users: A council which could influence service delivery and planning while supporting its members, who live with intellectual disabilities and some with reduced decision making capacity or communication challenges. This paper is a collective work and intends to provide a description of the pilot work of setting up this
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council. It is based on reflections from: the service users and their fears and excitement of increasing involvement and subsequent rewards and responsibilities; the organisation’s manager and the challenges in working within a service provider framework and some of the unexpected changes for staff and Board Members and; the project consultant and her reflection on the training and skills development required of all stakeholders.

The organisational context
Traditionally people with intellectual disabilities have had little support outside their families for meaningful leisure activities (Zijlstra & Vlaskamp, 2005). Kira Incorporated (Kira) was established in 1992 by a group of parents who desired more for their adult children with intellectual disabilities than what could be offered from a sheltered workshop environment. This group of parents had a vision to provide a place where people would learn and have fun. Over the past 17 years Kira has evolved to be a pre-qualified Alternative to Employment Service (ATE) provider funded by the Disability Services Commission (DSC) of Western Australia (WA).

Currently Kira provides services to 70 Members who are adults who live with an intellectual disability. The organisation is governed by a voluntary Board of Management, and the staffing structure is that of one Manager, a Program Co-ordinator and a team of 15 Community Support Workers.

Each of the 70 Members has their own individualised ATE plan, designed with and for them. Each person’s plan details their personal goals and aspirations they are working towards in line with the DSC-ATE outcome areas of social participation, personal independence, lifelong learning and enhanced support networks. Kira delivers programs to its Members both within the Kira Centre in Greenwood WA, and out in the community. Members are provided with the opportunity to participate in a variety of activities all of which promote development within the aforementioned outcome areas. While programs are primarily delivered in small groups, individuals who express a desire to receive one-to-one support are provided with individualised service.

Service-user involvement project background
Critics of service user involvement, sometimes go so far as to claim that the fundamental changes required for real empowerment could never happen in organisations (Forbes & Sashidharan, 1997). The manner in which Kira was initially established (by families as opposed to by an organisation or government) cemented a culture that deemed all of its service delivery to be responsive to the individual. Kira has always ‘listened’ to its member group to ensure that ‘consumer involvement’ occurred at the basic service delivery level. There were times though, where it was felt that some unintentional disempowerment of
Members was occurring: An example being when Members' comments might not be taken particularly seriously by a staff member or management/Board of Management. While some excellent work was occurring at Kira, there were also some areas in which the 'lip service' to values was not improving the skills and/or self esteem of Members.

As part of its commitment to improving service-user based services, Kira management undertook to explicitly underpin its services with the principles of Person Centered Planning (PCP) (O'Brien, 2004). PCP itself is a philosophy of service provision in which the choice and control of the service user is maximised by supporting their personal visions and goals for their lives – with the client at the centre of all planning and thus controlling their choices.

In July 2008 during intensive hands-on staff PCP training, the level at which Kira 'involved' consumers was challenged, meaning that the existing culture of service provision at Kira was challenged – despite its historical approach which included and valued member involvement. While PCP principles emphasise the importance of individual choice and control, any extended service user involvement was more the occasional opinion gathering around individual service provision than decision making at an organisational level, a culture which Stalker (1999) suggests is a common limitation of the level of extension of PCP in organisations.

During philosophical discussions amongst the support staff team, questions were asked as to the true value of the service-user involvement that was occurring. This led to support workers and management asking difficult values-based questions. While there was never denying the intent was to empower and involve consumers at Kira, it was seen that perhaps the reality of the amount of 'power' Kira was 'allowing' people was definitely in question. A paradigm shift in the planning and management of Kira services started.

The new question was: **How can Kira change our daily practice to ensure that the expertise of Members, about their needs and values, is acknowledged and acted upon in a way which will inform the strategic direction, planning, and management of Kira?**

The Kira staff response lead to casual conversations with Kira Members, to ask them to reflect on their involvement in service planning and provision. An early example of Member response which made a clear point was the discovery that service users did not like being called 'clients' (at which time the term Member was quickly adopted). Further service specific examples became quickly apparent. One example came from one long-time Member who responded to questions about the organisation's planning and management with: “I have been waiting for years for someone to ask me that sort of question, I have been..."
wanting to get the kitchen menu changed for a long time but no one ever asked me what I thought”.

While the basic principles of PCP had already been in place and Members were being further and further involved in their individual plans for services, it became apparent that their involvement in service planning and management per se was tokenistic at best. The responses of management and staff to this realisation differed for individuals, but collectively there was a realisation that some kinds of changes were needed to address the tokenism which had surreptitiously crept into Kira practices – despite all good intent to do otherwise.

**The birth of Kira Council**

The power behind naming and discussing the issue of authentic Member involvement had many small and yet powerful outcomes to daily practice of support workers at Kira. PCP principles were further applied to Member recreation, and conversations continued around changing the Member-staff culture.

These conversations, discussions and energies between staff and Members then brought about another topic: Why does Kira not have a committee or council of existing Kira Members? Why was there not Members as full Board members? Like many small contemporary non-profit disability organisations, the Board of Management of Kira is voluntary and since inception has been dominated by family of Members in its membership. While there is no clear answer to why Members themselves had not been asked to nominate for Board of Management positions, it is fair to reflect that the diminished intellectual and cognitive capacity of the Members was likely a factor in their invisibility. It simply reflected the history of the beliefs of capacity about people with intellectual disabilities.

While there was respect for the fact that many Members lacked executive functioning, and experienced cognitive difficulties in decision making to the point many have appointed legal guardians, the question was still raised as to how a group of service users could provide an alternative dimension to the governance of Kira – within their particular capabilities? The Kira positive ‘can do’ culture underpinned the beginning of what is now known as the Kira Council.

The first step, driven by the theme of diminishing tokenism, was to canvass Members to see if they were interested in a Member committee for Kira. After some education regarding what a Kira Council might do, there was an excited “let’s do this” from some Members. It is also critical to note here that while many staff, family and other Kira stakeholders were keen to make positive changes, there was also fear and concern that comes with such change.
At this time (and purely a coincidence) Kira had received a grant from the Independent Living Centre (ILC) to (amongst other things) further develop its information kit to potential and existing Members to make them more accessible. Sparked by the PCP training, and subsequent conversations with Kira Members, the question was asked: Why should the new Kira information kit, which is aimed at people with disabilities, be written and formatted by someone without a disability? The new-found non-tokenistic culture of Kira led to discussions culminating in the attitude that surely it would make more sense for existing Kira Members to provide all of the information, after all, they are the people that use the service, have the disabilities. How else could an information kit for Kira really be effective for other people with disabilities who wanted to know more about Kira? It was seen then the first project to be proposed to Council for their input could be the formatting of the information kit.

Hunter and Ritchie (2007) claim that effective individual co-production (partnerships) require transparency at all levels of service provision and “holds service providers more accountable for performance.” The forming of Kira Council, and having a hands-on project for them to commence their work with, demonstrated that Kira was up for this challenge. With Board approval, the manager secured an outside consultant (known to the organisation and who had provided the PCP training to staff) to assist with further staff and Member training requirements. The manager also appointed a key support worker to facilitate the Kira Council and provide practical support where required. In the initial phase, Kira Council was set up as a pilot project.

The early management decisions were largely pragmatic ones. The initial group of Members were invited to participate on Council, after discussions with them about (a) desire to do so and (b) the impact this might have on their individual services at Kira. All Members chosen, attended Kira on a particular day which was then the afternoon set aside for this purpose.

**Kira Council Project Aims**

While the birth of the Kira Council was clearly based on PCP principles and the provision of an environment for the empowerment of Members, the aims for Kira Council were based in the desire for increased democratisation of the Kira planning and management processes. The Kira Council aims also fitted well with values of the DSC as funding body and contemporary social model of disability values as well. In particular the Disability Service Standard of Choice (Disability Services Commission) and its relationship to self determination and self and peer advocacy were forefront in the minds of the pilot project team.

It was clearly not as simple as asking this group of Members: “What do you want”? The pilot team were aware of the sometimes narrow experience that PWID have with decision making.
and service provision as well as communication issues (Bradshaw, 2008). It was deemed critical that clear and transparent aims for Council were collaboratively set with them, to combat other known issues of providing PWID consultation opportunities which Collins and Stein (1989) identified as: potential opportunities for furthering manipulation; lessening Member control; increasing degrees of tokenism; and limiting real access to power.

Early aims for the pilot of Kira Council were transparent to Members, management and staff – although this didn’t stop robust discussion about their value or purpose. The initial aims of Kira Council were:

- to establish a means of support for Members to come together for formal meetings to discuss any concerns that they had, any ideas that they had and who would collectively represent the greater Kira Membership;
- to provide training and up-skillling in the interpersonal and organisational skills required to take part in governance style meetings and learn meeting skills, decision making (collective and individual) and democratic processes;
- to provide an environment where Members would learn about the more complex issues of service provision to assist them with their decision making; and
- provide opportunities where Members had actual control over the management of their service.

Kira Council began meeting every Wednesday afternoon, with the assistance of the key support worker. Their initial task was setting their operational guidelines, rule meetings and decision making processes – all of which had to be done with consideration of their differing communication styles. While they accepted the challenge of creating the Kira Information Kit with the consultant, they also set up two Member driven tasks for themselves – being a new logo for Kira and designing and making Kira Council badges.

**Training for staff**

Hunter and Ritchie (2007: 18) argue that for effective co-production to occur, service providers are required to have a “high level of consciousness about role and accountability”. Despite Kira staff having recently undertaken 12 months training and implementation of PCP prior to the implementation to Kira Council, it became apparent that staff were quite challenged by the concept of Kira Council (Council) once it became apparent that it meant that Council would be providing feedback on services and negotiating change in how services would be provided. Due to some of the staff reactions, additional staff training and mentoring was provided around client rights, Member empowerment and duty of care.
According to Hunter and Ritchie (2007: 18) successful co-production requires the “specific skills of facilitation, trust-building, reflecting, negotiation, resource-finding, interpretation and conflict management”: thus specific mentoring was initially undertaken with the key staff member who was to support the Kira Council Members. This staff member was a senior support worker and also demonstrated a commitment to the key values and the project itself. Ongoing mentoring was provided by the Consultant and continued from the Manager, particularly in areas linked to eliciting Member opinions, and supporting them in developing choice and the associated responsibilities in the organisational context. When complemented on the effective facilitation of Council growth, this key support worker replied: “Oh all I did was steer them in the right direction so they could do what they wanted to do.”

Further managerial support was required when the support worker employed to facilitate council had to cope with some antagonism from his peers. Very quickly Council was seen as an ‘elite’ group who got special treatment within Kira (a label which came about because we initially served cake at the council meetings), this has lessened as time has gone on, but still exists to some extent.

Kira staff were continually challenged by the subtle changes that were occurring both in and outside of Council meetings. Hunter and Ritchie (2007: 18) “professional and personal ethics come under pressure when people make choices which carry high risks or which appear not to be in their best interest, and professional codes of practice will not offer a guide to action in every situation.” This resulted in some backlash from support staff when Council appeared to make choices and the number and level of discussions amongst staff regarding ethics, values and rights increased.

One example of this is when the council decided to have a healthy option for Friday lunch – usually a sausage sizzle- and soup was decided as the winter option. Staff used every single reason you can think of to not implement this – not enough staff on to cook the soup, the rights of non Council members, finally resorting to the statement that “the other Members don’t like soup”. All of these excuses were transparent; it was the staff who did not like the idea. When it was pointed out to staff that they had initially implemented the sausages simply because it made their Friday easier and no one had asked one single client if they wanted sausages it took the wind out of their sails: Not one Member complained about having soup for lunch when it was implemented!

Management immediately recognised that not unlike the example in Mordey and Crutchfield (2004:10), in their review of a similar process in working with people in supported accommodation there was a “need to be prepared to change the boundaries and accept new
ways of conducting our affairs and working together.” Much of the values based training was done through role modelling by management and the key support worker, as well as formal and informal discussions on the various ‘hot topics’ which arose.

**Training for Council Members**

The learning styles of Kira Council Members was taken into consideration, and all training has been experiential and immediately applied to Council tasks. For example, training on democratic decision making was undertaken at a number of stages including: the initial meeting when decisions had to be made about practical meeting matters; the second meeting when discussion ensued about how people would be voted on and off Council; involvement of the entire Kira Membership group in designing and choosing a new logo for Kira. Particular aspects of meetings which were covered included: effective meeting communication, protocols and etiquette, agendas and meeting notes and minutes, and following up on actions. The learning of these often had to be repeated due to cognitive disabilities, but also due to some turnover in Council. When Council were asked about skills they felt they learned in the early days they added items such as: voting, asking for guidance, hosting, communicating with others with disabilities and responsibility.

At every stage of the creation of Council, support from the support worker, manager and consultant was to provide information in appropriate communication styles, to enable Council to make the choices they felt were best. This required significant support as Members learned the responsibilities that came with such decision making. As the decision making was on behalf of other Members, this was sometimes a difficult concept to grasp – although a current Council member recently described it as “*helping people, really it is just about trying to help others*”.

Further specific training was provided in response to Council need when working on different projects. These include: training for Council on the difference between being a Council Member and being a staff member; and having to incorporate duty of care for Council Members - explaining that as staff are actually employed they have a duty of care to ‘clients’ and Council Members role is different. This was a difficult concept to get across, and it is unclear if this has been successful as it is an issue that continues to arise. Issues which have arisen regarding this included Council Members wanting to do first aid certificates as they felt they had to have these in order to be an effective Council Member. There have also been issues with council Members ‘telling off’ other Members and threatening to have them expelled from Kira “because they were being naughty”. This lead to lots of interesting conversations and some confronting situations where we had to explore with staff who the
council Members were modelling from! These issues have assisted Kira management to further clearly define the roles of staff, Board, management and Council.

An example of project specific training for Council Members includes public speaking (for a variety of settings and audience), meeting and greeting visitors to Kira, providing guided tours of Kira, quoting processes, research, hosting, accessing resources, creating documents and design processes. While these tasks were initially met as challenges for Council, there has always been at least one (usually more) Council member willing to learn the required skills for projects they have either devised or agreed to do. This resulted in one Council member declaring: “Now I interact better with all people”.

**Challenges for Staff**

Reflecting on the initial pilot of Kira Council, it would be fair to say that Kira Council Members faced their individual challenges with the support of the mentors around them. The same has also been required of staff and management. Hunter and Ritchie (2007: 18) claim that “...co-production exposes staff to ambiguity, uncertainty and challenge, sources of stress and discomfort which have to be balanced by strong and sophisticated support and supervision, whether from peers or agency managers”. Apart from formal training, open space discussions have been encouraged formally at staff meetings and informally with the manager.

The greatest challenge has been the perceived threat to power, and some staff had real problems with this. The initial concept was accepted well, but when it came to putting empowerment into practice, some staff responses indicated some levels of resistance, and even stress.

With the increasing knowledge of staff responsibilities by Council members has come challenges of direct support work processes. In one meeting Council raised the implementation of the State Disability Service Standards (Disability Services Commission) by Kira staff. They had observed some behavioural management practices by staff and called into question these practices in line with the standards. These intelligent and pointed questions then involved conversations with Council about the need to view every situation as individual. Council members also learned that they may witness only a small part of an interaction between staff and Members and there might be more information about the situation than it was appropriate for peers to know about under the Privacy Act. More interestingly this then had to be raised with the staff – who took collective offence to the fact that their work practices were actually under review by the people whom they were “employed to serve”. This was one example of many emotive responses as staff witnessed changes in power relationships.
A resulting lesson for many staff has been that when you truly provide an empowering environment, it is not always comfortable, easy or trouble free. The lesson has been that sometimes when you empower someone else the price is a level of discomfort for you – a sense of your personal values or choices being challenged – some staff are now more comfortable with this concept, but not all.

**Challenges for Management**
In the early days of piloting Kira Council, there was excitement at the possibilities, and accompanying concerns regarding reactions of various Kira stakeholders. The extra mentoring, providing space for support for all stakeholders and need to be available for Management decision making with Council were time laden activities. The time needed to undertake effective service user involvement and co-production appears to be a common experience and yet difficult to quantify and plan for (Mordey and Crutchfield 2004; Fyson, McBride and Myers 2004; Hunter and Ritchie 2004).

The Board are now more comfortable with the whole concept of a client council, however initially there was a great degree of reservation to implementing council, previous experience had tainted people’s opinions. As time has gone on the Board now take Council seriously – an illustration of this was the inclusion in the AGM of a Council report and a Council Member presenting the report.

For the manager, who largely drove the project internally, the challenges were experienced as professional and personal development:

“I have found the whole process to be very enlightening, to observe the staff dynamics shift to embrace empowerment has been very rewarding and frustrating! To witness the personal growth in individual council Members has been incredible, to have a sense of confidence in council in ‘letting’ them speak for themselves, at meetings, or presentations has been a real professional buzz, with a distinct reinforcement of what is ‘right’.”

Thus the contribution of the time required has been overall seen to be worthwhile on a number of levels, and the mentoring and informal training around staff challenges and reactions resulted in a new paradigm of service provision at Kira.

**Useful Lessons Learned**
Things which the pilot team would do differently if doing this again include:

- Provide more initial training with staff, challenging them with concepts before they occur, and providing more values based training;
• Provide more initial training with council Members, being really clear about roles and responsibilities so that blurring is minimised.; and

• More open discussion with parents and significant others, as sometimes it has felt like these people are ‘out of the loop’ with regard to where Council was up to – or were considering Council as “just another Kira program” on the calendar.

Where to next?
Kira Council is now in its second year – and well past its pilot phase. No stakeholders have considered disbanding Council and it has developed its own structure and agendas since the pilot days. Future aims being explored with Council include:

• To truly sit alongside the Board, becoming a part of the overall governance of Kira.

• To meet out of Kira normal working hours (with whatever supports are required to achieve this) to minimise the risk that it will become “just another Kira program”. This will also place true value on it – questioning whether people should be using their ATE dollars to participate in Council, or if they should be a volunteer like the rest of the Board. This will also open up the possibility for a greater Membership of council, unlike presently where Membership is restricted by the day Council runs on.

• To have a representative on the Board, with voting rights.

• To have a Council representative on employment panels.

The implementation of Kira Council has been a challenge of co-production. The central lessons were in regard to providing quality and focussed training and mentoring for all stakeholders. Benefits to Kira Members have been linked to: expressed raised sense of self, skills development and increased sense of responsibility. The rewards for everyone involved has been a continual values-based challenge – one which all stakeholders have had the opportunity to grow from.

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References


