

A NEGLECTED RESOURCE: KEY ROLES FOR FAMILIES AND CONSUMERS IN THE EVALUATION OF COMMUNITY SERVICES

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INTRODUCTION

Standards and Monitoring Services Trust (SAMS) was started by a group of family members and staff, to evaluate residential services of the biggest New Zealand service provider in 1980. We began by looking at individual homes, then at day programmes, schools, and since that time our work has branched out into evaluating a very wide range of community services for people with disabilities.

The majority of work SAMS undertakes in NZ is using evaluation as a tool to assist services to develop. For this reason our process varies significantly from compliance audits or accreditation models. We see our task as that of gathering the perspectives of stakeholders, matching their experiences against agreed standards and performance indicators then signalling the next potential steps for service development.

Approximately 97% of the services evaluated in the 1300 evaluations we have undertaken (covering approximately 3000 facilities) provide long-term support.

These are primarily non-Government agencies providing services for people with an Intellectual Disability, Physical Disability or significant mental health challenges. Although they are non government organizations most of their funding comes through contracts with government. These services are not providing a transitory intervention, but medium to long-term support systems. They range from intensive 24 hour care to occasional support to people living semi-independently in integrated settings.

Our ability to accurately measure change over time, Quality of Life and effective ethical practice is crucial. We are not involved in evaluating a small temporary component of an individual's life, but the impact that a service has on a person's entire lifestyle. Our process and reports must be robust, have integrity and be comprehensive. Our reports need to serve as a catalyst for positive change.

We know from data we have collected that the SAMS process does achieve positive change. Recently we conducted an effectiveness review (May 2000) of Mental Health evaluations in New Zealand's South Island. This involved reports on twelve services, where we had made a total of seventy-three recommendations. Ninety percent of recommendations had been actioned within sixteen months of the original evaluation, I largely we believe because of our collaborative, Multi-perspective approach (Benjamin, Capie and Nossin 1998) which involves consumers and families as key players in all aspects of our evaluation process

KEY ROLES for CONSUMERS and FAMILY MEMBERS

The effectiveness of the SAMS process, and our mandate for involvement in the Disability field, comes from the active participation of a network of trained and accredited consumers and family members.

As individuals, this group invests time and energy in being evaluation team members. The group ensures that, as an evaluation agency, SAMS retains a clear focus on pragmatic and positive service development. As a group of consumers and family members they strive to discover new ways that SAMS will guarantee that the views of consumers and family members are equitably represented in the process and outcomes of SAMS evaluations.

Many of the consumers and family members who are involved with our process have had dealings with compliance audit and accreditation models. They understand, too well, that there is a world of difference between processes that seek to establish the existence of “paper” protocols and procedures, and evaluation processes, like SAMS, that are more interested in “how” a procedure was developed and whether the practice is inclusive, effective and ethical according to the perspectives of the different stakeholder groups (McConkey 1996)

SOME FUNDAMENTAL QUESTIONS

It is perhaps helpful, if before we go any further we ask some fundamental questions:

- Who has the greatest vested interest in ensuring that agencies provide inclusive, effective and ethical services?
- Who is already trained to be sensitised to the covert indicators that something is working or not working?
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- Who is most suited to breaking down barriers and enabling consumers and families receiving a service to feel safe to express their opinions?

SAMS would, without hesitation, claim that consumers and families are the most suitably qualified in all of these areas. Given training, support and an enabling framework, consumers and families are the most skilled practitioners of evaluation in this area.

Why?.

Family members and consumers have a vested interest that goes far deeper and far wider than the average altruistic or empowerment-focussed professional.

It is their lives or the lives of their sons and daughters, and the quality of these lives that is at stake.

A review of SAMS evaluations undertaken since 1/7/1991 in the field of Intellectual Disability shows that Family members/consumers led 60.8% of the SAMS teams and Y% of team members were family members or consumers.

In the Mental Health area where SAMS has had a shorter involvement, 71% of team members are people who identify themselves as Mental Health consumers, and 14% are family members.

The suggestion is sometimes made that in SAMS we are likely to raise consumer and family expectations only for these expectations to be eroded by the inevitable clashes with powerful agencies and systems that may see the world differently. . Do we take enthusiastic, passionate and sensitised people, call them “evaluators”, then throw them into an environment where protocols, precedence and strategic manipulation can so easily confound?.

No, that does not happen, and it does not happen because SAMS has a process, developed over many years, to train and accredit consumers and family members wishing to be evaluation team members. To enable consumers and family members to be key players in evaluation SAMS ensures that individuals are assisted to develop attitudes, skills and frameworks to be safe and effective.(Benjamin ,Capie ,Nossin 1997)

TRAINING TO BE AN EVALUATOR

To become a SAMS “evaluator” or evaluation team leader will involve a person in approximately two hundred and fifty hours of training. To be an evaluation team member will initially require a person to participate in 50 hours of training. Currently, something like 75% of SAMS evaluation team leaders are family members or consumers

Broadly speaking, the SAMS training process involves an individual in two, twenty-five hour, training courses and approximately two hundred hours of graduated supervised practical experience. During the training process individuals are made aware of the philosophy and practice of the SAMS Multi-perspective approach to evaluation.

Topics covered during training include questioning skills, negotiation skills, organisational development, positive reframing, consensus, objectivity, organisational skills and report writing. While in training as an evaluator people receive verbal and written feedback about their areas of strength and areas that need to be further developed. It is not a process for the faint hearted but a process that tries to ensure that consumers and family members are validated and equipped with the skills that are necessary to facilitate an effective service development evaluation.

At the core of our approach and training is the belief that evaluation is about partnership or collaboration.

INFORMATION GATHERING IN EVALUATIONS

The other component to consumer and family participation in evaluation is, of course, how consumers and families are involved in providing information to evaluation teams. At its core, the SAMS Multi-perspective approach enables the evaluation team to equitably represent the different views of defined groups, and compare the outcomes for the differing groups. SAMS developed a transparent approach which provides in-depth information that relates views on the same issues, from the

perspective of differing defined groups. The challenge then becomes “how can we create equity?”.

Traditionally, there have been barriers to the consumers of services and their families experiencing an equal ability to provide information to evaluation teams. To begin to explore how equity can be achieved we must consider the following issues.

Consumers and families need:

- a. To know that the evaluation is occurring
- b. Information on the purpose, processes and potential outcomes of the evaluation
- c. To feel safe that information provided will not have negative repercussions
- d. An idea of options as they may have limited experiences and expectations on which to base comparative judgements
- e. A flexible process that takes into account the fact that they are not paid to be there
- f. Information presented in a language and manner that is understandable
- g. To know that involvement in the process will have a meaningful outcome.

During a SAMS internal consistency review, conducted in early 2001, it was established that when we evaluate services approximately one third of our contact time is with the agency management and staff, one third is with consumers of the service, and one third of the time is related to contact with families. The quantity of time spent with each stakeholder group may be a poor indication of the quality of the opportunity or information however. Methods that we use to increase the chances that the opportunities we provide consumers and families are of most value are to:

1. Ensure that consumers or family members are present as evaluators
2. Make sure that our process is transparent
3. Discuss how we ensure confidentiality at every interview or group meeting
4. Use open questioning, positive reframing to assist individuals to express opinions, aspirations and ideals.
5. Offer to meet people away from the service and at times and locations that are out of usual working hours
6. Encourage consumers and families to be present at meetings where feedback is given and recommendations are discussed

With the SAMS Multi-Perspective Approach a forum is provided where people with different perspectives have some opportunity to experience equity. The base assumption SAMS carries is that when individuals work together all parties can benefit. Strength and innovation come from unity in diversity. Evaluation can provide funders with feedback on the effectiveness of where they place the taxpayers dollar, consumers become active partners, carers/whanau are respected as influential, management receives information for strategic planning, staff obtain feedback and all involved can find common ground on which to celebrate and strategise. Effective evaluation leaves individuals and organisations with more than the sum total of their

individual contributions. The SAMS approach, since 1979, has aimed at being collaborative.

A COLLABORATIVE APPROACH.

Collaboration means working in combination. It is a united action where there is a union of different perspectives. Collaboration is not about sameness or uniformity but rather weaving different threads into the same garment. A prerequisite for collaboration is the belief that unity can be formed in diversity. We don't need to see the world the same way to have a contribution to the whole. It is collaboration when we, together, develop goals and then decide on how we will achieve them. Collaborative evaluation is not about inviting consumers and families to participate in a process that has already been determined. Collaboration is about all the parties joining together to create both the terms of reference and the process.

SAMS view is that evaluation is a path to service development. An evaluation report may be a required outcome of the process but it is not the destination. It is a step towards a shared understanding and a collective vision. It contains strategies for positive change. The real and enduring effectiveness of evaluation is not determined by a certificate on the wall or a bewildering array of grades and statistics. The effectiveness of evaluation is related to the degree that it can enhance people's lives and be a catalyst for development. Collaborative, multi-perspective, evaluation assists people to walk, with direction and energy, down a path of hope.

Compliance to minimum standards does not excite many consumers, families or providers. The opportunity to improve lives does. If our destination is excellence then minimum standards may be an important initial step – but surely not the goal. Partnerships where consumers, family members, agencies and evaluators work together can be messy, chaotic and challenging. However constructive change and meaningful lives often come from a dynamic and inclusive environment.

Bibliography: -to follow.

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