



Is Anyone Better Off?

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Pact is a relatively large (by New Zealand standards) Non-Government Organisation in the South Island that supports people with intellectual disabilities and/or mental health problems to live fulfilling lives in the community. Pact provides a range of services for more than 700 people in Otago, Southland and the West Coast. These services include community support, supported accommodation, services for Maori, high and complex needs, day programmes, respite services, supported independent living and services for children. Our focus is to enable people to have successful lives in the community. To achieve this end, the mainstay of our staffing is made up of non-clinical staff with a wide range of skills and life experiences. However, we also work closely with clinical teams and do employ a range of clinical staff. Providing such a wide range of *community*-based services means that using the Health of the Nation Outcome Scales (HoNoS) system to measure outcomes is not a suitable tool for Pact. Instead, we needed to develop a system tailored to both our non-clinical efforts and the wide range of people we support. This is not to say that we are denouncing HoNoS. For people with mental health issues, Pact's tool should be used in conjunction with HoNoS.

In this presentation, we will begin by discussing some of the problems we faced in setting up a meaningful outcomes tool – specifically, how we could ensure that it measured quality of life as opposed to merely quality of systems. We will discuss our tool in some detail, before moving on to consider some of the problems the tool may face and some likely solutions. Finally, we'll sum up and discuss how using our approach means that many of our staff have 'bought into' and are keen to become champions of this project.

Devising a method by which we could effectively measure client outcomes has been a goal of Pact's for many years. However, for a long time the project was put into the 'too hard' basket. We faced the same challenges that most of you will have experienced – problems with using a quantitative approach by which to rate the quality of people's lives and the difficulty of devising a tool to meet the wide range of people that we support. Perhaps the largest obstacle was the trepidation from staff members about the efficacy and appropriateness of making such measurements. Many of these staff had in mind the sorts of measurements that were used in the 1970s and 80s – the percentage compliance with safety regulations, the frequency and length of support required, mortality rates and so on. This means that, as much as anything, one of our goals was to change the attitudes of many of the staff within our organisation. We had to convince our staff that a measurable outcomes system was not going to be just another bureaucratic burden; that the tool was not merely going to measure the quality of our systems. We were adamant that our tool was going to be an effective mechanism to measure the quality of the clients' lives – a bold proposition. More specifically, we want to measure the areas in which Pact is making a positive difference in people's lives and the areas in which we could do better. We want to be able to make educated and deliberate decisions that have a positive impact on the lives of the people that we support. Not only did we have to devise a tool that met these expectations, we also had to convince our staff that the tool was going to be worthwhile. So, how did we tackle this dual challenge?



Enter Mark Friedman – our veritable God of measuring outcomes. Friedman’s approach focuses on the question “*Is anybody better off?*” Friedman acknowledges that we also need to measure how much we did and how well we did it. However, he says that these measurements are only relevant insofar as they help determine whether anybody is better off. Friedman points out that in the business world, profit is the bottom-line. Businesses might measure the average time it takes to make a certain item, but this is only relevant because it impacts on profit. In the non-profit sector, the bottom line is whether anybody is better off. We should only measure things like bed nights and percentage compliance with audits if we can demonstrate a link between these things and improvements for the people we support. Improvement in quality of life is the engine that drives performance improvement for Pact. If we’re not improving clients’ quality of life, then there’s not much point in us being here.

Now we face the problem of demonstrating that we’ve made an improvement in the lives of the people we support. It’s relatively easy to measure the number of bed nights that have been filled, the percentage of compliancy with health and safety audits and so on. It’s much more difficult to measure whether an individual’s quality of life has improved. The number of things that impact on one’s quality of life is enormous. It might be something as trivial as a smile from a stranger, or it might be a much more significant event such as the loss of your job or a family member. A multi-elemental approach spanning a wide range of areas is essential to get a true reflection of how well Pact is supporting its clients. We’re not going to bore you with the details of how we decided on the areas that need to be included to measure quality of life. What we will say is that a review of the literature reveals that there is considerable agreement on the areas that need to be measured. To follow the language used in the literature, we have called these areas ‘domains.’ So, the eight domains are:

1. Interpersonal relations
2. Social inclusion
3. Personal development
4. Physical Wellbeing
5. Self-Determination
6. Material Wellbeing
7. Emotional Wellbeing, and
8. Rights

That step seemed to be fairly simple. (Of course, it’s never quite as simple as it appears and we have made things a little more complex by adding the domain of ‘organisational wellbeing’, but we’ll come back to that shortly.) We now have eight areas that need to be measured. If we ask questions in each of these domains then we can be reasonably sure that we will cover the range of areas that impact on quality of life. For example, we recognise that liking the people with whom you live has an impact on quality of life, so this question was included in the interpersonal relations domain. Having good physical health also impacts on people’s emotional wellbeing and their overall quality of life, so questions regarding healthy lifestyles and access to health professionals were also included in the measurements.

In the handouts you have, you will see a page titled Personal Development. We have a page like this for each of the domains just mentioned. Each domain begins with a statement about what is important regarding that domain for the people that we support. You might notice that the statements could relate to just about anybody – not just those people with intellectual disabilities and/or mental health problems. That’s



because the people that we support basically have the same wants and needs as everybody else.

Next, we list a few customised and calculated measures for each domain. Some of these measurements relate to all clients, while others are restricted to certain groups of clients. The questions that relate to all clients were asked as broadly as possible. For example, we ask whether the client has learnt more skills in order to become more independent. These skills could range from making a cup of tea to gaining your driver's license. Asking the question in this way allows it to be interpreted to be relevant to each person. The Senior Support Workers in conjunction with team leaders (and with the assistance of clients) rate these questions from 1-5. This allows for the observations of the people that know each client best to be translated into outcomes.

Questions 3 and 4 are examples of where the question has been restricted to a certain group of clients. As noted at the outset, Pact supports a wide range of people. At one end, Pact supports people who have a profound intellectual disability, are non-verbal, and require all personal cares to be carried out and will need to be supported in both residential accommodation and in the community for the rest of their lives. Pact also supports people with mental health problems. Some of these people require long-term residential support, other may use the crisis respite service for a short period. Yet others will only require a minimal amount of support in the community (i.e. a few hours a week) for a short period of time, until they get back on top of things. As you can see, for some people the support provided by Pact is almost all pervasive. Other clients are less dependent on the services Pact provides. This is not to say that the role Pact plays is of diminished importance, but instead that we need to measure different things to ensure that we are doing the best we can for the different categories of people we support. The wide range of people means that some measurements will be appropriate for some of our clients but not for others.

Have a look at the 'Personal Development' domain. In question three, we ask whether the client has made progress to move through the Pact system and be successfully reintegrated into the community. This question is intended to measure whether those clients with mental health issues have made steps to become less dependent on Pact support – whether they have been able to deal with their mental health issues so that they are more able to live in the community in the presence or absence of their mental illness. It would be unduly idealistic to ask of a person with a profound intellectual disability, whether they have moved through the Pact system as realistically most (but not all) of these clients will need support for the rest of their lives.

Also on each page are some notes that are relevant to the questions. It allows the question to be explained in more detail and gives some justification for why a certain question was asked or why it was worded in a particular way. Next are the limitations of the question. We recognise that the questions are not fail-safe and that they may not be entirely applicable to every single person that we support. In this section, we note any issues and ways to minimise these. We also recognise that some things cannot always be adequately portrayed using a solely quantitative approach. Hence, our tool allows for qualitative or anecdotal notes to be made. This will help to ensure that if the questions do not adequately reflect or capture the client's wellbeing, we know the 'true' picture rather than simply having a superficial number. Finally, the data source is noted on the page, if one is known



Previously, I mentioned that we had added a ninth domain to the commonly used eight domains. Those domains all relate to the clients – whether the client has improved social skills, material wellbeing and so on. There are some additional areas which do not directly relate to the client, but instead concern the effective running and management of Pact services. Let's go back to Mark Friedman's approach. He says that the most important question to ask is whether anybody is better off; whether we have made an improvement in the quality of life of the people we support. He also says that the things that used to be measured in the 80's (such as audit compliancy and staff turnover) may be measured so long as they help determine whether anybody is better off.

We think that some of these things most definitely do relate to client wellbeing. It is important that Pact is well staffed and meets its audit requirements, in order to ensure that a high quality service is being provided to clients. The eight domains that relate to the client fall into the bottom, right-hand quadrant of the diagram. The additional domain which we have called 'organisational wellbeing' measures the other three quadrants. In this domain we ask, for example, whether Pact is well staffed, keeps its staff happy and has a low staff turnover. We also ask whether Pact has a positive reputation in the community, both with other service providers and organisations such as the police, schools and WINZ. We ask these questions because we think they impact on the clients' quality of life. Take staffing issues for example. If we have a stable, happy and well-skilled workforce, then clients will become more relaxed with their support works and will be able to achieve more. If we have good relations with other organisations then we can ensure that we are providing the best possible range of services to our clients.

So we have discussed the tool itself. Now we need to consider how we are going to use it to ensure that the things that we are doing are improving the clients' lives. Friedman talks about the idea of 'turning the curve'. It's a fairly basic notion that is used frequently in the business world, but is relatively foreign to the NGO sector. One of the measurements we make in the physical wellbeing section is the extent to which people lead healthy lifestyles. Now, let's say that we ask this question and we find that we score quite poorly – that lots of the people we support don't live particularly healthy lifestyles. Now, we know that generally speaking an improvement in the healthiness of one's lifestyle will improve one's quality of life. Armed with those two pieces of information we can make some informed and deliberate changes to improve the healthiness of the client's lifestyles. We might, for example, start a new walking group or place more emphasis on smoking cessation programmes. Some time after we've started these new initiatives, we will take the measurements again and from this we'll be able to determine whether these initiatives have been successful – and ultimately, whether they've improved the clients' quality of life. Using Friedman's clear terminology, we'll be able to see whether we have turned the curve or not. If we make certain changes at time t and from then on we see an improvement, we know that the changes have been worthwhile. It's not rocket science. It's basic, but it works – everyone can understand the notion of turning the curve, and everybody can work towards getting the curve pointing in the right direction. We can use the curve to find out where we're doing not so well and to reward ourselves when we can see we're making a positive change in the clients' lives.

Some of you might rebut that there are loads of things that impact on an individual's quality of life, and it would be presumptuous of us to take responsibility (whether it be credit or blame) for turning the curve. They would argue that lots of things could impact on whether someone leads a healthy lifestyle or not. For example, a person working towards a healthier lifestyle could have little to do with Pact efforts. The client might be involved with another organisation that implemented a different, more effective



programme. Or it might just be that the individual had a change of heart, and decided, of their own volition, to lead a healthier lifestyle. All this could be true, but we do not accept it as a criticism of our programme. We are not setting out to *prove* a cause and effect relationship between Pact initiatives and an improvement in the clients' quality of life. What we are interested in is whether the client's quality of life has been improved, not who has done it. As Friedman says, chaos and complexity theory tells us that cause and effect in complex systems is difficult, if not impossible to determine. People are complex creatures, which means that the cause of changes in behaviour are likely to be both multi-elemental and difficult to determine with any certainty. However, using a common sense approach, we can be fairly confident in saying that if we make changes, then see a 'turn in the curve', that those changes were at least part of the cause of the improvement. We are looking for intuitive, instinctive evidence of improvement. We are not looking to *prove* that *Pact* was the only contributor to that improvement.

To conclude, there is loads of scientifically driven information about outcome measures. Coupled with the scientific approach are problems concerning cause and effect, how to maintain consistency across scorers and so on. Although we accept that all these are legitimate problems we have taken a more instinctive or intuitive approach. The work of Mark Friedman inspired us to focus on what we can do; rather than focusing on the problems. Using Friedman's approach we need to answer two questions:

1. What quality of change did we produce? And
2. Is anyone better off?

Those of us who have worked in the area for some time already know what improves the quality of life for our clients. Using the wealth of knowledge of our front line support staff, we can tailor common sense measures to suit the wide range of people that we support. We can see where we're doing well, and we can see areas that need improvement. Finally, we found that using a simplistic approach that focuses on whether anybody is better off was the vehicle that we needed to change the negative attitude of many staff. Staff bought in to the project when they realised that we were not using an overly-scientific or cumbersome system, but a system that focused on common-sense and achieving positive outcomes for the clients. Everyone seems to agree that there is little point in measuring outcomes unless they show that the client is better off. We need to take that and use it as the focus of our project so that it gains support and credibility throughout the organisation.