

CRUCIAL TIMES

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Guest Editorial

Margaret Rodgers

This edition of Crucial Times focuses on the topic of practical leadership. Leadership is a topic that is very close to CRU's heart and, we believe, an appropriate choice as we bring you this edition of Crucial Times after a considerable interval.

For many years, CRU has stated that it exists to support the development of leadership and authentic change, which enhance the possibilities for people with disabilities to belong to and participate in community life. To achieve this, CRU aims to both demonstrate leadership in what it does and also to intentionally 'grow' and develop leaders to lead the change that needs to happen. Since the early 1990s, CRU has worked very deliberately to recognise, support, develop, mentor and connect the leaders in the sector and it continues to be one of our strategic goals in 2010. We know that there are many people with disabilities, family members, and workers in different roles and different types of organizations demonstrating leadership across our State. In this edition we offer further examples from interstate and overseas.

Leadership is still a word that causes some confusion. Sometimes we mix up the difference between leadership and management. I like the way that Jim Kouzes and Barry Posner talk about the difference between Leadership and Management. They say the root of the word lead means to go, travel, guide and so leadership implies a sense of movement. Leaders 'go first' and are pioneers as they begin the quest for a new order. They venture into unexplored territory and guide us to new and unfamiliar destinations. On the other hand the root of the word manage is hand, and therefore management is about keeping things in

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CRUs Mission Statement

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

hand or handling resources, maintaining order and organization. This helps to illustrate the core difference, and at times tension, between these two important functions – the difference between handling things to maintain order and to actively go seeking change. We appreciate that good, values based management is critical but that is not what we are talking about in this edition.

Sometimes we also think that only people in formal leadership roles can demonstrate leadership and we tell ourselves ‘they’ should do something. However, if we follow the thinking that leadership implies a sense of movement, then process will be more important than position or place. There is not one process to fit all leadership challenges but elements of the process would include starting with the initial spark of an idea or belief that something could or should be different; making a decision or taking a stand to do something about it; taking the time to gather the resources needed; enlisting and engaging others who bring a range of skills and abilities and being committed and responsible over time. I think you will recognise these elements in the following articles, demonstrated in a variety of different arenas and leadership styles.

These articles also illustrate people in formal leadership roles doing more than their role dictated to create things that didn’t already exist. Leading the process or journey of change to somewhere or something new is more likely to be successful if driven by passion and persistence rather than holding a particular position.

That’s not to say that people in formal leadership roles won’t be passionate about leadership and change, but we don’t need to wait for them or leave it all to them. Change is everybody’s business and so leadership can also be everybody’s business. This may involve changing our message from ‘they’ should do something to ‘we’ should do something.

In his book on leadership, James MacGregor Burns declares, “The ultimate test of practical leadership is the realization of intended, real change that meets people’s enduring needs.”

I think you will find that the following articles more than pass the test.

Margaret Rodgers.

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CRU gratefully acknowledges the contribution of Gemma Scott and Michael Kendrick in the creation of this issue of CRUcial Times.

From The President.

It's been a while but CRUcial Times is back. It feels like we are welcoming a lost friend home again and there is so much to catch up on, so many stories to share. New faces, some old faces and a brand spanking new office. Certainly too there is plenty to write about and we look forward to sharing insights, perspectives and stories with you again through CRUcial Times. So with some pride and definite excitement, I herald our "re-emergence" edition.

This is my first opportunity as CRU's President to write for CRUcial times. In preparing for this task I went back and reviewed our past issues since 2001. Surprisingly we haven't had an issue on the topic of leadership since then even though it has been an enduring concern and focus of effort within CRU from its beginning. Many past articles and pieces have addressed concerns and problems that certainly had the threads of practical leadership running through them. CRU has devoted much of its time and resources to understanding leadership, identifying potential leaders and sustaining leadership through challenging times. It is therefore timely and particularly pleasing to bring this edition to our readers.

Leadership has been a key focus for CRU for many years, indeed for probably most of its 22 years of operation. One of our current strategic goals is about leadership and leadership development. It's also been a focus for my own work for more than a decade. So having this confluence of my day job (teaching leadership to final year students who will work in human services) and my CRU role is both challenging and exciting. I have watched people struggle with the demands of management in systems only to find that what is really needed is ethical and practical leadership.

For many people working in systems, the path that is often presented as the only way is to become a manager or administrator. But what we really need are leaders. As Stephen Covey says: Management is efficiency in climbing the ladder of success; leadership determines whether the ladder is leaning against the right wall. How do we know if we are against the right wall? We need astute wise leaders to ensure that we are.

So what are the qualities of good leaders and good leadership? Peter Drucker, another writer in this area says:

Leadership is not magnetic personality that can just as well be a glib tongue. It is not "making friends and influencing people", that is flattery. Leadership is lifting a person's vision to higher sights, the raising of a person's performance to a higher standard, the building of a personality beyond its normal limitations.

It is important to note here that practical leaders are all sorts of people found in all sorts of places. We all have met inspirational people who indeed "lift our vision to higher sights". They may be quiet and unobtrusive or loud advocates. They can be in positions of power in formal systems or passionate and dogged behind the scenes. They are people in for the long haul.

Leadership styles are many and varied according to the person, the situation and who is following. Transformational leadership has some particular relevance to our work at CRU. Transformational leadership is an approach that is about change in individuals and social systems. It aims to create valuable and positive change in the followers with the end goal of developing followers into leaders. We are after all about valuable and positive change and we need to develop leaders for the future. I think contributors to this edition have much to share that is of great value.

Lesley Chenoweth
President

The Nature of Practical Leadership

Michael Kendrick is well known throughout the world for his extensive work as an educator, advocate, consultant and author. He is Canadian but now lives in Massachusetts, United States. He has a deep interest in ethical leadership, service quality and the creation of safeguards for vulnerable people. Michael has been a regular visitor to Queensland for over 20 years so brings knowledge and understanding of local and national issues, as well as an international perspective on the issues that people with disability and their supporters face as they strive to live in their community. Michael's website www.kendrickconsulting.org contains further information and links to his writings on a wide range of subjects.

The Nature of Practical Leadership

Though much is said about leadership, it is often hard to know what it will mean in practice, as words and deeds may seem plausible at first glance, but be revealed by later events to have been off the mark. Given this ambiguity, it is unavoidable that potential leaders and their proposals will be greeted with scepticism and this doubtfulness may be warranted. The same cannot be said for leaders that have actually been tested by events and have established a track record of impressive results. These are leaders whose words and accomplishments are there to be examined first hand, thereby making it possible to more confidently conclude that they did exercise effective leadership. By working out what they specifically did that ensured a beneficial outcome, it also becomes possible to understand the basis of their success. Though many people may miss the significance, there is great advantage to studying and drawing upon the insight, wisdom and experience of leaders who have actually made a difference in the real world and have something to show for it. These are leaders whose values, example, thinking, methods and priorities are not speculative or untested, but have shown potency and efficacy. Learning from them is consequently justified, at least within the limitations of their accomplishments. They are, by right of their track record, "practical" leaders.

Practical leaders can be drawn from any walk of life and background, so there is no group in society that is somehow endowed with greater leadership capacity. It is often easy enough for privileged groups and individuals to gain formal roles of leadership. This simply gives them access to institutional authority and resources, but it does not in any way assure that they will actually achieve anything of merit. Actual leadership accomplishments require that beneficial changes be made in the real world and in the case of service to one's fellow human beings; it requires that people's lives did genuinely improve for the better. By looking for instances where this has occurred, it becomes possible to work out retrospectively what the specific and positive leadership contribution actually was.

In this edition of Crucial Times, a variety of examples of

beneficial leadership from a number of countries have been selected because of what had been achieved, but also because of the various types of leadership challenges they successfully addressed and the kind of leadership that was needed to do so.

In the case of Washington State in the United States there has been a sustained effort by a collection of like minded leaders for several decades or longer to expand the number of people with disabilities who have regular jobs in the community. Prior to the recent deep recession the State of Washington had been able to improve its community employment rate for people with disabilities to 70%. In other words seven out of ten people with disabilities were regularly working in the community on an averaged basis.

A small self directed home support project supporting aged persons with dementia in Dunedin, New Zealand, a highly person centered and empowering small service, was able to generate strikingly positive results in the lives of people by keeping them well supported in their own home and personal lifestyles and networks. Notably, this was done at a cost that was significantly lower than what it would have cost to institutionalize these persons.

The story of SAMS, a long running and innovative New Zealand initiative, allows us to see leadership being expressed in finding ways that service quality issues can be routinely evaluated first hand by service users and families and in which service evaluation can be moved from an auditing model to a developmental model, thereby emphasizing quality enhancement.

Also in New Zealand, in the Auckland region, were several related efforts to ensure that people with a history of persistent mental illness could successfully establish homes and lifestyles of their own design that would make it unnecessary for them to rely upon traditional 24/7 staffed group home living. In the process, these people ended up needing much less staff support and demonstrated that it was better from a recovery viewpoint to place an emphasis on relationship, values and vision and meeting needs normatively.

In Western Australia, a governmental initiative was

undertaken, involving many hundreds of people, to develop an overall strategic plan to ensure that as many of the benefits of community living could be made available for the greatest number of persons with disabilities. This eventually resulted in a high level of consensus embodied in strategic plan with a very strong value base in terms of good lives for people in the community.

In each of these examples, we see practical leadership at work in generating beneficial outcomes for those people in our communities that are often at risk of social devaluation, marginalization and exclusion i.e. aged persons, persons with mental illness and persons with disabilities as well as the people in their lives, personal networks and communities. These changes manifested at many levels, including at very personal levels as well as agency, systems and community change. It is noteworthy that achieving these changes was, in every instance, complicated and inherently challenging, yet they occurred through the deliberate efforts of people who were committed to getting results.

Key Ingredients of Practical Leadership

• The Recognition Of Where Leadership Is Needed

It is useful to note what the examples outlined in this edition can show us in terms of what constitutes practical leadership. It begins with the recognition, in each instance, that something important needed doing in the world. In several examples we see that this began with unhappiness with what the effects of custodial residential care settings were and would be for people with dementia and persons with mental illness. In another, it was the recognition that if progressive change in governmental strategy were to develop, it would require the building of a community wide consensus on values and direction. Similarly, in Washington State, it was not simply that an emerging consensus was intentionally fostered that regular individualized community employment would be possible for much larger numbers of people with disabilities. The vision extended to the recognition that the challenge was multi dimensional and would only yield to long term, coordinated and persistent leadership at a variety of levels. In all instances, the basis for this ability to make

an informed determination about what might be needed in the world, did not come about from the thoughts and actions of just one person acting alone, but more typically it involved various forms of collective leadership i.e. individual leaders acting jointly with others. For example, in the instance of the developmental evaluations, service quality was seen as eventually improving, not simply through the conduct of evaluations, but rather through the process of consciousness raising and discussion about quality that was built into evaluations. In effect, this acted as a catalyst and joined up the efforts of numerous individual staff people interested in quality with the quality agenda of SAMS, thereby magnifying the interest in what was needed.

• A Willingness To Engage Constructive Proposals For Change

The world has ample unaddressed problems requiring leadership. What practical leaders do is to meet and engage these problems by constructing, as best as can be managed, proposals that establish a better way forward. Remedying the unemployment and underemployment of people with disabilities is an extensive multi-year and multi dimensional challenge, as is supporting people with dementia to obtain quality lifestyles. Nonetheless, in both instances a positive way forward was imagined and pursued thereby not leaving the originating problem neglected and unaddressed. The problems were faced “head on” and a constructive

antidote was fashioned and implemented. In effect, such leaders took on responsibility for the problem so to be sure that progress would be made.

• A Willingness To Bear The Costs And Difficulties Of Change

Avoiding challenging problems can be quite appealing to many, as it typically does not ask anything of them and it can help avoid taking on onerous and demanding responsibilities. It is, however, a surefire recipe for ineffectuality. Little is achieved in the real world until people, especially leaders, are willing to pay the price for change through a decision to take on its inherent costs and burdens. Rarely are these entirely known in advance, but it can be realized very early on that there will be such demands and that meeting them is

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the only way forward. The whole area of public policy in disability or any other sector is riddled with incipient conflicts, divisions, controversies and vested interests, yet all of these parties and interests will need to be fully engaged if a meaningful and durable consensus on positive strategy is to emerge from the body politic, sufficient for a government to act. It would be easier to not open up such a “can of worms”, but this would come at the price of establishing positive direction. Practical leaders know and accept that everything has a price and that all advances will demand something proportional to the challenge of the leaders involved.

• ***Commitment And Perseverance In Getting The Job Done***

Few challenges yield easily. It is the people who are prepared to stay the course and see things through to the end are more likely to succeed than those who lack commitment and perseverance. Those who lack the necessary determination and resolve simply will not withstand the demands that will come with change. We can see that in the example of SAMS which has over a twenty year track record of conducting evaluations, within a still innovative framework, despite many years in which it was not that clear whether SAMS would survive. Similarly, it takes considerable resolve to patiently and respectfully enter into the lives of many people with persistent mental illness and gradually help them as they rebuild their lives. Such commitments are typically open ended enough that there is very little option but to accept that it will require of leadership to do “whatever it takes” with no assurance in advance that good things will prevail.

• ***Embracing Realistic Idealism***

It is not very likely that people will improve very much in themselves and the world unless they set some sort of ideal for themselves. These sorts of ideals challenge people and define what is being sought. Normally, this means eventually bringing something into the world that was not there, but is nonetheless needed if people are to benefit and thrive. Ideals, properly pursued, tend to bring out the best in people, as it asks people to do and be better. This is reinforced by the challenge of “imagining better” that is embodied in any process of proposal development for what any needed change should optimally look like. This was at the crux of the exercises to define what the good life could be for people with mental illness or dementia, much as it was in the effort to build a guiding consensus on community living.

However, ideals are not singularly sufficient, as it is important that people be practical enough to make the ideals manifest into real results in daily life. Idealism needs to be coupled with realism in order to manifest its potential. Obviously, seeking to have more people

with disabilities employed is praiseworthy, but it is quite another thing to actually get people jobs in practice. Hence, we can see the value of practical idealists taking on leadership challenges.

• ***Selecting Strategies That Work***

We live at a time when many people confuse goals and intentions with actual achievements on the ground. However, there is a vast distance between words and deeds and it is always challenging to find the best means to help words become transformed into effective action. A key element in this regard will be whether the leaders involved were careful in their selection of implementation strategies that would largely ensure that the results being sought would be attained in practice. This requires the ability in leaders to be able to discern and distinguish operational strategies that are feasible and effective from those that are not. Intentions are not enough, as the means for actualizing these must work in practice. When people actually obtain real homes of their own and lifestyles that help them thrive, then we can be sure that sound means have been selected, as the results speak for themselves.

• ***Magnifying Impact Through Strategic Alliances With Others***

There is a temptation to cast personal leadership into the genre of being due to some sort of exceptional qualities in a few select people. This is not actually consistent with how things get accomplished in the real world, as few people, even those with strikingly above average talent, can get much done unless others cooperate with them. Competence with the art of gaining that necessary cooperation and support is a key feature of practical leaders whether the initiative is large or small, as ensuing that people are “pulling together” will make all challenges that much easier and increase the likelihood of eventual success. It takes all kinds of people acting with similar intent to change service quality and service models. However, if these people are invested in and come to share the same vision, then gaining the ground to get there is made much more achievable.

• ***Investing In Renewal And Rebuilding***

All hard challenges will take their toll on the people who commit themselves to achieving them. So, if they have no means available to them to recharge and revitalize their efforts, it is predictable that they will become a spent force. If they can rebuild and renew themselves and their efforts periodically they can fend off the stagnation, fatigue, demoralization and loss of focus and priority that are ever present dangers in terms of moving forward and offsetting decline. The very fact that we see change efforts in

Washington State, New Zealand and elsewhere that have maintained their vitality for decades clearly suggests that renewal and rebuilding strategies had been employed on many occasions in order to achieve such lengthy track records. Practical leaders must be able to sustain ambitious and demanding initiatives and this makes renewal not only desirable, but a necessity.

Practical leadership clearly exists and it is always

valuable to be alert to its presence and the many valuable things it can reveal to us. This is only possible because those offering such leadership actually did accomplish something important in the world. It is this track record that signals practical leaders from impractical ones and it should be obvious as to which leaders will have the soundest guidance to offer others.

Creating change to increase personalisation in mental health services in New Zealand.

Ross Phillips is Director of Inclusion Solutions, an organisation based in Auckland, New Zealand, and committed to service and policy and workforce development that promotes increased experiences of social inclusion for marginalised groups. His work and research interests include participatory research and practice approaches, measures of social inclusion, impacts of individualised service design, and social constructions of risk.

This article consists of my reflections on significant positive changes that have occurred within mental health service provision in New Zealand in recent years. The factors that have contributed to positive changes will be highlighted in the hope that others may identify and strengthen their own efforts at creating change. Two initiatives in particular concerned recreating and renegotiating personalised living and support arrangements for people who were previously only offered 24-hour services provided in congregate, provider-governed, group living arrangements. Both initiatives were delivered within the Auckland region of New Zealand.

The first was a small pilot scheme whereby a model of supported living was designed and developed to assist people to live meaningful lives in homes and communities of their choosing. A major intent of this small pilot was to disabuse service providers, funders and planners of the often held view that service provision in group homes was the only way to support people who were 'assessed' as requiring twenty-four hour care. Not surprisingly, as twenty-four hour care was the only funded service delivery approach for people who required significant support, this is what people were commonly assessed as requiring. The project successfully proved that many people did not require around-the-clock care or containment at all. The second was a much larger service initiative, serving a far greater number of people with a similar intent of creating personalised service supports and assisting service users to lead enhanced lives in their communities of choice. There were conditions that were common to both initiatives that were critical to success. Whilst there are pros and cons of the two different approaches (small and large scale) the

success factors will be discussed together. Following this will be a discussion on the challenges faced in maintaining a strong focus on the personalisation of service delivery.

Creating Change #1: Leadership

This change is listed first as it was critical to all of the other success factors for change identified in this paper. Leadership in the first instance required people within the service system to determine that there was value in 'doing something better.' Leaders created both a vision of what might be possible and a determination to see it occur. Both projects had a clearly indicated goal and strong leadership from the outset to convince others of the value and worth of the goal.

Leadership was enacted throughout all aspects of the services - from managers, frontline service staff to service users and their families. Service users were encouraged to take an active lead in the design and development of their personalised supports. Service systems that were established to ensure ongoing improvements and positive developments actively promoted service user leadership also by inclusion in service development structures.

Personal leadership was critical from the frontline service staff. A significant principle of both services was that the quality of the relationships with the people served was the cornerstone of service delivery. The idea was to develop relationships between support staff and service recipients that were ethical, valuing, empowering, deeply respectful, competent and responsive. These relationships became, in some

ways, the predominant features of the services. The recipients of the pilot all reported a significant degree of satisfaction with the way they were treated and viewed as equal partners in the process and the relationship. People who had good reason (due to historical experiences) to distrust the intent and the intervention of support staff found that this very intervention was the beginning of belief in recovery. That is, it was the belief and value that the staff had of the people they served, that gave those people the opportunity to pursue hopeful activities and to have faith in their own abilities to achieve their desires. Having staff take a lead in the creation of these deep and trusting relationships with service users was critical.

The other aspect of leadership that was present in both initiatives was that there was a dedicated position or function whose role was to provide inspiration, support and encouragement to staff and to provide stewardship of the values of the service. Motivating staff to continue working towards the purpose and to use the vision, values and ethic of the service to influence their decision-making was another feature of these roles.

The need for renewal was an important aspect of leadership. Both service initiatives started with significant energy, motivation and enthusiasm. This was in part due to the new nature of the services however it was important to continue investing in the things that bring energy and enthusiasm. Consistent leadership that provided motivation was one way of doing this, the other was to use service users' voices and successes and to include service user successes as a means of outcome measurement. Over time it will be important for the services to keep developing leaders who constantly challenge staff to remain passionate and committed to the values of the service.

Creating Change #2: Clarity of Purpose

Both service initiatives were explicit in their intent and ambition. Opportunities were constantly sought to express and promote the values that informed the services. This clarity of purpose became a unifying 'call to arms' for the many staff involved and helped service staff to challenge barriers to service user recovery. Both services had strong principles of person-centred planning, self-determination and community engagement and development.

The larger service initiative involved six different non-government organisations in the service delivery whilst the smaller initiative involved only one. The larger initiative needed a much more formalised and organised attempt at clarifying and delivering to purpose given the increased likelihood of providers delivering services with a different focus.

This occurred through the creation of collaborative service improvement structures including a service improvement group with representatives from all organisations involved, a collaboration agreement, a joint staff capacity building forum for sharing innovations and motivations and a joint training and workforce development programme. This meant that the purpose and ethic of service delivery was constantly able to be clarified, strengthened and reviewed for relevance. It also allowed services to evaluate their performance against these ethics between each other.

Creating Change #3: Investing in Staff

This paper earlier referred to the requirement of individual staff to take a leadership role in the challenging work that they were doing. This occurred in two ways. One was by attracting the right kind of staff in the first instance and the second was by investing in the capabilities of those same staff. The nature of these service changes were such that staff were expected to be constantly challenged by this work. Staff were expected to be creative, resourceful, authentic and able to cope with significant complexities. There was an acute awareness from all involved that the quality of support staff was critical. The ability for staff to work "with" people and support them to be their own solutions was an essential skill. This required investment into the capability of staff to think innovatively about how services could meet the self-expressed needs of service users. For service users to both determine and be the solution to the problems they face, they had to trust that support staff were going to assist that process. Support staff had to learn that equality of relationship was an important factor and a focusing point of service delivery for both approaches.

Both of the service initiatives intentionally placed a greater emphasis on the humanity of the person carrying the professional staff function than on the actual function itself. When service staff were authentically present to the person being served there was an expressed experience of genuine warmth, regard, involvement and interest – a relationship based on mutual admiration rather than service requirements to meet an obligation. A significant outcome of this was the degree to which staff were meaningfully influenced and affected by the service recipient also. This has a number of consequences. First, it created an environment where the answers to situations sat with the relationship rather than with the professional. This has an immediate empowering affect whereby the role of 'needy, helpless, passive recipient of service' is usurped by one of 'active participant' in the control and destiny of one's life. Second, it impacts on the organisation of service delivery. Most organisations' rhetoric indicates the

primary importance of the person being served. By authentically relating to people, these service initiatives created an ethic that actually achieved this often espoused rhetoric.

For the larger programme an intentional training and workforce development programme was created. Service users and their families were consulted by an independent evaluator, and identified a wide range of attributes and skills that were of upmost importance when it came to their support staff.

Leaders with experience in developing service innovations were also consulted and together documented key workforce development requirements and the beginnings of training programme called Personalised Solutions Training. This has since been refined and continually delivered to ensure that the key skills and attributes of people delivering service remain relevant. A further workforce initiative was the group facilitated "Capacity Building" supervision sessions whereby staff from different organisations regularly came together to share positive stories of successes, innovative solutions and community resources. These sessions occurred with the intent of building staff resiliency, sharing successes and hope, and having the opportunity to be re-energised and recharged by the work of colleagues from different organisations. Both of these investments in staff also provided opportunity for the leaders of the initiative to strengthen the collective purpose and ensure that service delivery remained aligned to service intent and philosophy.

Creating Change #4: Building Partnerships with Service Users

A feature of both service initiatives was a pool of funding (flexible-funding) that was not applied to either a formalised staff member or a 'bed' in a service. The idea behind the funding was that it was to be applied in a flexible, creative and innovative way in order to assist in achieving service user goals of living well in the community. This was a significant departure from previous service delivery models that 'pre-determined solutions' by purchasing services prior to individuals even being identified. Service Users were involved in creating this personalised solutions and this has been a safeguard to ensure that the funding is used in the way it was intended.

An interesting, but essentially unavoidable, paradox occurred whereby project participants were afforded the opportunity to 'do without' formalised mental health services. When a service undertakes to truly get to know and work with people it soon appreciates that often what the person requires, or how they could have their needs met, does not lay within the provision of formalised services responses. That is, the solution to problematic situations or needs, when formulated 'with' a person, looks substantially different than it would if formulated by a group of people making decisions 'for' a person. Solutions driven by people within a framework of trust and partnership are significantly more appropriate and powerful than those that are not.

Creating Change #5: Focusing on Community

The final common feature of change in these two service initiatives was the intentional and explicit focus on building community around people. Services and service staff were encouraged to have a strong focus on creating inclusion in community. The flexifund was often most creatively applied in supporting service users to gain active employment, attend educational opportunities, and become involved in community clubs, resources and agencies. There was a strong focus on building and strengthening service users' natural communities. Interventions that built service users' sense of belonging to a community group or likely increased their social connections were lauded as examples of 'best practice'.

Likewise a focus of both services was the inclusion and involvement of family members in the design and delivery of service to an individual. Many stories and examples were shared of service users being supported to reconnect with families and strengthen their familial relationships and roles.

For the larger initiative there was a focus not just on building community for one person at a time but also the responsibility for a broader approach to community engagement to facilitate access to community living. This meant time spent working closely with housing agencies, local clubs, employment (and unemployment) services, and other such community resources was encouraged and measured. The intent was to build the ability and willingness of communities to respond. The providers all noticed that as more time was spent developing these relationships with local community entities

Even with the utmost
vigilance it is easy
to slip into creating
solutions with people
on the basis of what
you have
had success
with previously

they were much more responsive to service users. There is less reliance upon mental health services to provide services that are readily available within local communities – housing and employment are two immediate examples. This contributes significantly to combating stigma and discriminatory attitudes within communities. Indeed one service providers experience was that the time spent with a tenancy agency in developing relationships and providing information, education and support, led to the tenancy agency moving from being reluctant to offer a tenancy to a service user to now approaching that provider asking if they have any service users who require rental accommodations. This experience of exposure is a critical destigmatisation strategy.

Both of these initiatives were exposed to the very real challenges of sustaining positive change. Whilst some of these challenges were common others, related particularly to size and approach, were unique. The smaller pilot was particularly new and was testing the approach with a small number of people. This meant that the change factors listed in this paper were intensified as there were less numbers of staff to lead and less people to influence. There was also an imbued enthusiasm by both the staff and the participating service users due to the novel and inventive nature of the pilot. However its comparative size lead to a vulnerability – that of other agents of the bureaucratic service system making decisions about its future without consideration or input from the people using the service. The pilot nature of the initiative was such that decisions for discontinuation were able to be made by people distant from the reality of the lives of those who gained some benefit from the service.

The other initiative served approximately three-hundred people and had strong support from funders; however its size also brought a number of significant challenges. Creating and maintaining quality – so that all service users were engaged in deep and reciprocal relationships with their service staff; were instrumental in designing and determining through service solutions and were supported to strengthen their naturalised supports and communities was a challenge. With the much larger number of service users and the larger number of staff maintaining a focus on the intended values of the service needed to be much greater. As staff that were close to the original intent of purpose move on they can take with them the close understandings of the intent and philosophy of service. Likewise leadership can begin to lose focus on the important values of the service (and the implications of these) as initial leaders move on. The larger service type ran the very real risk of becoming routine and simply a new form of standardised service delivery. Service providers can begin to place priority on ‘equality’ wanting to ensure that everyone has equal access to opportunities,

however they run the risk of missing the nuance of individual lives and subsequently creating rules that result in a lack of ‘quality’ for many. In delivering training to these services recently this was reinforced in a declaration by a new staff member that “we don’t do that”. When asked further it was apparent that there were a number of generic decrees from this service provider about particular uses of the flexifunding – the challenge of this from a personalisation perspective is that these ‘across the board’ applications of what is and isn’t possible results in people having to ‘fit’ the service rather than the service being uniquely tailored and built to ‘fit’ them.

From a staff perspective there is a very real challenge of what I have termed resisting the ‘known’. Even with the utmost vigilance it is easy to slip into creating solutions with people on the basis of what you have had success with previously. Worryingly, it is also easy to steer people towards creating solutions that you believe are more likely to be considered acceptable to others (often management). Both of these personalisation initiatives did not successfully locate the authorisation of expenditure with the person receiving services. Subsequently, a challenge for each was to ensure that the people authorising expenditure were critically aware of, and practicing, the values of the services. Additionally it was important that the systems for authorisation were not intrusive for service users or difficult for staff to follow. This can be challenging for providers operating within climates of funding accountabilities. Where this was made more manageable it was due to key people within the funding system having a belief in the service values and intent, a trust in the providers delivering service, hope in the ability of service users to lead full and safe lives in the community and a willingness to take risks. Indeed, for the larger service initiative funding and planning managers took a strong leadership role championing the need for creativity, flexibility, personalisation and community capacity building.

Whilst neither of these service initiatives were without their challenges and need for improvements they were two of a growing number of similar services that are being developed and delivered in the mental health sector in New Zealand. Overall, the impact of these service types are still being measured and evaluated. It is important that the critical aspects that make them successful are continually discussed, shared and used to inform ongoing improvements to how they are delivered. Whilst this paper identified some of the common conditions that led to successful changes it should be noted that many of these are vulnerable to changes in philosophy, funding and personnel. It is important to consider how to fortify against this to prevent these personalised services from simply becoming new forms of institutionalisation – simply that which occur one person at a time.

A West Australian example of influencing systems change by developing personalised and creative community living options

Mr Eddie Bartnik has worked extensively in the human services sector with a particular emphasis in the disability and community services area. He was recently appointed as Western Australia's first Mental Health Commissioner. He has experience in changing disability service systems and making them more responsive to individual needs. He has had a key role in the development and implementation of the Local Area Coordination approach and its subsequent implementation nationally and overseas

Picture this: a man with a disability who has moved out into his new home sharing arrangement and is bursting with the happiness, optimism and security of having his own home in his local community and feeling secure. A mother who shares her story of the network building and planning, leading up to her son now moving out into his own home. The challenges of having faith, creative thinking and letting go are all part of this amazing journey.

This is an evening workshop hosted by the Disability Services Commission's Local Area Coordinators at the local community club, attended by some 50 family members and local service providers all gathered to hear more about the new West Australian state government Community Living Initiative.

It is still early days but already this has become a compelling story that I am delighted to share with you. This workshop is one of dozens of regular events now happening across Western Australia which are planned on a local basis with individuals and families and are generating a new tide of optimism and positive momentum. It is a story of not only partnering with families, service providers and policy makers across the state to generate a big vision of possibility but also about then creating the policy framework and technical support on the ground that can assist individuals and families to plan and achieve practical outcomes, on a step by step basis. The background, processes and outcomes so far of the Community Living Initiative will now be outlined as an example of a systemic change process.

Background to the Community Living Plan for Western Australia

In 2006 the state Minister for Disability Services commissioned a Sector Health Check on Disability Services in Western Australia. After extensive investigation and consultation, the "Disability Services Sector Health Check 2007 Report" was published and included a clear direction to increase the range

of community living options available to people with disabilities, with increased emphasis on no/low cost community support and more flexible and innovative options. Specific recommendations from the report included the development of a Community Living Plan, exploring and reporting on innovative options with demonstrated success in other states and countries, and building a second layer of expertise around innovative community living options.

As Project Director for the Community Living Plan, it was clear that a change of focus was needed - a focus outside of traditional models and providers and towards new pathways and partnerships. This included an enhancement of individualised planning, options exploration and technical (practical) support as well as a "big dose of vision building." These new options would need to be "person centred" and emphasise key elements of a good life such as valued relationships, choice, contribution, security for the future, and challenge. Options would need to be sustainable, cost effective and demonstrate strengths based preventative approach.

The key deliverables for the project included:

- A Stage 1 Concept Plan - An information resource of innovative support options locally, nationally and internationally, a review of alternative planning pathways and partnership mechanisms and a new conceptual framework for community living that includes a vision statement, principles, strategies and broad measures of change.
- Then a Stage 2 Implementation Plan - a range of practical steps and measures for each of the seven main strategy areas for the period 2008-11

The complete project methodology is outlined in the Community Living Concept Plan Stage 1 report (August 2008), however for the purpose of this article some key project processes are highlighted as follows:

- A Project Reference Group was established for both stages of the Project
- Stage 1 involved a series of statewide consultations that engaged people in a workshop type format where several innovative models and examples were presented to assist people to “imagine better”.
- Public submissions were invited as well as commissioned presentations to the Reference group by international consultants Michael Kendrick (Key features of an individualised personal approach) and Heather Simmons (Person Centred Planning)
- A 2 day facilitated writing workshop where a statewide group of 30 participants from various backgrounds drafted the new Framework for Community Living (February 2008)
- Presentation of the Community Living Concept Plan Stage 1 Report (August 2008) and the web based Information Resource (with direct links to all primary sources)
- Two 1 day facilitated writing workshops to draft the new Policy and Funding Framework for Community Living and the Community Living Implementation Plan (August 2008)
- Establishment of a new Community Living Resource Team and a new Community Living Support funding Strategy (September 2008)
- Recruitment of Project Reference Group community members to the new independent Community Support Funding Panel (November 2008)
- Production of a new planning booklet for families and service providers “Looking forward to Community Living” (October 2008)
- A statewide series of Information Seminars to present the new Community living Support Funding strategy (from September 2008).
- Ongoing series of Local Community Living (vision building) workshops plus a Statewide Community Living Expo in November 2009

Thinking about new pathways and partnerships:

Discussions with families highlighted that planning in the area of community living has often been equated to planning for Accommodation Support Funding through the Combined Applications Process (CAP). Individuals and families can then be caught ‘waiting’ in a system that places focus on critical needs (usually defined negatively) and families often say that after a time of writing these critical needs type of funding applications, they are simply left ‘waiting in negativity’. Some people get funding but still can’t find what they want and others may have paid support but few genuine relationships and friendship.

The Sector Health Check report also identified a range of other risks that may be unintended consequences of the current system, for example, that some people believed that a successful CAP funding application is the only way of moving from the family home to a more independent option. There was general reluctance to plan for or trial alternative arrangements without having first secured funding. It seemed to result in a more generalised reduction in community capacity, with consequent isolation of people with disabilities. This occurs if the community comes to rely too heavily on funded supports rather than inclusive practices and informal supports particularly for people with mild to moderate disabilities.

It is a story of
partnering with
families, service
providers and
policy makers
across the state
to generate a big
vision of possibility

There is clearly a need for new planning pathways that build on people’s strengths, relationships and resources so that they can start to create the life that they want. High on everyone’s list when discussing what makes a good life are valued relationships, security for the future and making a contribution. However, it is also important to note that even very good human services have limitations when it comes to delivering these reciprocal personal relationships and sense of security, and that renewed importance must be placed on the contributions of family and friends, ordinary people and local communities. Al Etmanski, co founder of PLAN Canada, describes this as moving from ‘a scarcity framework’, where the main aim is the allocation and acquisition of scarce disability resources and funding, to ‘an abundance framework’, where each person’s fundamental need for opportunities for reciprocal relationships and contribution are paramount and where there is an abundant supply through ordinary people in local

communities. These new planning pathways require a change from seeing people with disabilities as 'service users' to 'active citizens', with themes of being included, making a contribution and being recognised, and directing your own life (see Bartnik 2008).

There are two main components of the vision for the Community Living Plan: firstly, the Commission's overarching vision statement that applies to all areas of the Commission; and secondly, the specific Community Living Plan vision statement.

The Disability Services Commission vision is that "All people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone." The vision for Community Living is for "All Western Australians to have the same opportunity: my own life, my own home, in communities where we all belong."

The key principles are grouped in a number of major theme areas as follows:

Core values

Some fundamental beliefs underpinning community living are that each person:

- is valued and respected for their uniqueness and capacity to make decisions
- has a right to real choices and ongoing opportunities for challenge and growth

Person centred approach

Community living must focus on:

- getting to know the person well, honoring their life so far, their strengths, gifts, goals, fears and dreams; and
- understanding the person in the context of their family, friends, culture, beliefs and community networks, and the primary importance of valued relationships in each person's life.

Information and high quality planning processes

In planning for a life in the community, people should have access to:

- timely, accurate and culturally relevant and accessible information from a variety of sources to enable people to consider alternatives and to make decisions about how and where to live;
- other individuals and families who can speak with authority and relevant experience about community living; and
- a range of planning processes that draw family, friends and supporters together to support the person to explore their vision and create practical strategies.

Partnerships for action

Transforming plans into action will require:

- shared responsibility from the person, family, friends, community, business, government and

services; and

- practical and technical support in areas such as communication, planning facilitation and network development.

Systems to support each person

To establish a good life in the community each person should have access to:

- flexible support and resources as needed to strengthen and complement personal and community networks; and
- a range of measures to keep people safe and secure.

Reflection and review

To sustain a good life over time each person should be able to:

- have confidence that their home and supports are secure; and
- have control over the review and change of their living and support arrangements.

Community Living Support Funding Strategy

An immediate implementation action arising from the Stage 1 Concept plan was the development of a new funding strategy to build on the energy and momentum that had been created. Many individuals and families indicated they had been planning for years, were ready to go and often only required modest amount of resources but had no funding source unless they were assessed to be in critical need. This strategy included budget funds of \$650,000 recurrent for approximately 40 people with funds individually allocated and able to be used flexibly with various options for self management. A new pathway established as a separate strategy commencing September 2008 with a new policy framework and funding process. It included some capital funding for housing. A Community Living Resource Team was established to assist people and their Local Area coordinators or service providers with technical support to develop, submit and implement plans.

The policy framework included four key objectives. The aim was to support people with a disability to have their own home and life in the community. To enable the person with a disability to have a choice in who provides the support and how the support is provided. We wanted to build on the strengths and capacities of people with disabilities, their families and networks and local community partnerships. Lastly, to increase and evaluate the range of innovative and flexible community support options, on a state-wide basis and with regard to cultural background.

Adults (or their families on their behalf) could submit a plan, provided they were eligible for specialist disability

services and not already receiving compensation for this purpose. It didn't matter whether the person was still at home, living independently or in some form of supported accommodation, provided their needs could be met with the maximum allocation of \$20,000 per annum recurrent community living support funding (they could however have post school options or alternatives to employment funding in addition to this amount). The criteria for funding were not the usual ones related to critical need: instead, they related to the personal outcomes for community living and the various "Building Blocks" related to planning and support. Individuals could submit a concept plan for development funding or a well developed plan for approval. Individuals could also specify that their individual plan was part of a collective project.

A key observation is that the initiative is growing from strength to strength due to the engagement with individuals and families as key partners in this process and the powerful impact of good local examples and inspiring local speakers who can speak with great personal authority about the planning journey and also the practical outcomes of their efforts so far. The statewide network of Local Area Coordinators and the Community Living Resource Team provide on the ground assistance to engage local people and map out next steps. Training initiatives are a critical capacity building strategy across all sectors and investments in person centred planning approaches and personal network development are key building blocks for families in particular. The evidence base is starting to demonstrate a high level of value for money

where relatively modest levels of funding are being used to generate substantial amounts of informal and community supports. Attention to quality, flexibility, safeguards and sustainability is crucial as part of the longitudinal evaluation. Most of all, the focus must remain clearly on each person and the sort of life and home that they wish to choose, in a community where they belong and are surrounded by people who value and care about them.

The success of the program initially related to the clear problem formulation in the Sector Health Check Report (2007) and a clear policy mandate and high level project leadership and support. There has been an emphasis on engagement and joint vision building, rather than the traditional form of consultation, leading to a strong sense of "co-production" and a "community of shared interest". It has been essential to elicit and listen to critical feedback and take this on board, for example with the need for practical resources for families. The project relied on a national and international perspective on best practice, with strong analysis and external critique, leading to a broad range of strategies to effect systems change. We found the engagement of key decision makers in policy development and implementation planning, leading to a creative and timely implementation plan with a commitment to action and practical results was critical. We maintain a commitment to safeguards including evaluation and policy review so that the focus on outcomes and quality is sustained.

A longer version of this article is available by contacting Community Resource Unit (CRU).

We are moving from 'a scarcity framework', where the main aim is the allocation and acquisition of scarce disability resources and funding, to 'an abundance framework', where each person's fundamental need for opportunities for reciprocal relationships and contribution are paramount and where there is an abundant supply through ordinary people in local communities...

Leading the change for older people in the community

Penny Hambleton is the Facilitator of two Individualised Funding projects in the provinces of Otago and Southland, NZ. Her work across the two projects enables her to witness the challenges that people requiring support are confronted with and their ability to solve these issues if given the liberty to do so. She has worked in the human services for over 30 years and commenced her journey as a registered nurse, prior to working in the quality management area. Penny has researched quality of life issues and policies around frail elders who require support but choose to live in their own home.

Lorna Sullivan is Chief Executive of Standards Plus, a small, national agency in New Zealand working as a community resource to promote innovation and change in the delivery of services and the development of community for people with disability and families. Her particular areas of interest are in working alongside people with disability and families to build services and supports that are genuinely relevant to their needs and their individual pursuit of personally meaningful futures. She uses what she learns to support people with disabilities and their families, advocacy groups, service providers, and governments interested in working for genuine change.

This paper concerns itself with a very small but important attempt in New Zealand to influence change for the better in the lives of older people who faced great risks in terms of losing control of their lives and becoming institutionalised. The challenge that was faced was to put in place options for these individuals that were authentically person centred. An independent evaluation of this initiative concluded that the results were impressive and positive. Much of what matters in any attempt to influence change is whether the leaders involved have a clear sense of the changes they want and why these are important. Consequently, this paper is a reflection on these important questions.

"It is me after all who knows him best" Pat quietly explained. Peter and his wife Pat had decided in the very early stages of Peter's diagnosis of Alzheimer's and in the knowledge of what lay ahead, that Peter would continue to live at home. It was what they both wanted and in the absence of being able to speak for himself anymore or speak at all, Pat remained committed to ensuring Peter remained where she felt he belonged and that was with her at their home. Pat also wanted to remain in charge of Peter's care and support. Pat had thoughtfully and artfully over the years adapted to the changes in Peter's memory and orientation, language, intellectual functioning and behaviours, and she was very clear about the things that still appeared to give Peter pleasure and meaning along with what he needed on a day to day basis.

For Peter, Alzheimer's disease had been running its 'robbing' course for about 12 years when his wife Pat put their hands up for individualised funding. There was mounting professional pressure that Pat should consider a move to residential care for Peter. She is clear about what and who she needs to enable her to both continue her own paid work and continue supporting Peter when she gets home at the end of each week day. With the assistance of individualised

funding that is equal to the current cost of residential placement in "psychogeriatric" hospital level care which Peter through the needs assessment process has been assessed at. Pat has been able to employ two support staff who over the week come into her and Peter's home when she leaves for work at 7.30am and stay "with" Peter until she returns at 6pm in the evening.

Currently there are 19 elders who have, either on their own volition or with the support of their families stepped forward to be part of this Project. Their desire for continued self determination is the common denominator amongst this small cohort, along with lives that in the main have been lived for a very long time and the distinct possibility of residential care placement. However, this is where any similarity ends, as each person has brought with them their own unique set of needs and circumstance.

Establishing a service that focuses on the person:

It is very rare that one gets the opportunity to begin to develop a service from scratch. This has been the case in a small project for older people that we have been operating with the Otago District Health Board (DHB) in Dunedin, New Zealand. What makes this project an interesting example of what it takes to be authentically person centred is that;

1. The project arose out of concerns that older people themselves and their families had over the support options that were available to them.
2. We were in a position of being able to negotiate an agreement whereby the process for accessing services, the amount of individual funding and the accountability to the funder are the only aspects of the service that are prescribed.
3. Our negotiation of this service was based on the

premise that older people and their families would have access to their own service dollars, either directly or supported, and would be the primary decision makers with regards to the nature and level of support they receive.

4. As much of the available dollar would go into the direct provision of service as possible. This meant the need to have as small a bureaucracy as possible.

These conditions provided us with the opportunity to begin to develop a service for each individual.

The struggle to stay focused on the person:

This small initiative has shown to us that the aspirations central to the lives of people can be nurtured even to the end of their lives. What it has also shown is how difficult it is for a traditional bureaucratic system to understand and accept that people, when they are given the option, may choose to live their lives differently from that which the systems believes to be right for them.

The struggle with a person centred approach has not come from the capacity of the person and their family to determine what makes sense in their lives. It has come from a deep resistance by a professionally dominated, risk averse bureaucratic system that begins with the premise that the answer they have for the lives of people is the only right one. So deeply rooted is this belief it persists despite the fact that this same bureaucracy embraces the language of person centeredness and has enabled such an individualised service to develop. Fundamentally, it would seem that the struggle to truly focus on the person is so difficult to achieve because the basic paradigm or premises under which we design and deliver our supports is not being questioned.

We are relying too heavily on systems, elite professionals and bureaucratic hierarchies to meet people's needs and act as if the right system will be the answer. Each year we put more money into services and supports that do not fundamentally change the lives of people with disability.

In addition, while we talk about the provision of person centred approaches we continue to develop and apply standardised systems. Yet standardised systems are best applied when we want the outcome to be the same each time. If what a person needs is understood to be unique to that person then a standardised approach is unlikely to achieve this. You can't be standardised and personalised at the

same time, yet this appears to be what our current bureaucracies are trying to achieve.

Bella's story highlights the need to commit to staying focused on the differing needs of each individual. Although at times it can be a struggle to commit to doing the best for each individual, Bella's story demonstrates that with creative thinking and authentic commitment, it is possible to create a unique life for each person. The challenge is to think outside the box, to remain flexible and make the impossible – possible.

A move to residential care after an episode in acute hospital care had left Bella aged 85, in her own words, "in despair". Her only son and daughter who no longer lived in the same town as Bella also shared their mother's anguish and it was decided between the three of them that Bella would relocate 150km down

the road to her son's house. Before making this move they all moved back to Bella's unit for 2 weeks to prepare for this time of large life transition for both Bella and her son Tony. The move back to Bella's home also made apparent that Bella at this point in time in spite of the efforts of faithful friends and neighbours did need somebody in the house fulltime. Bella and Tony describe the time preparing and making the move as "stressful". For Bella this is associated with the loss of her own home and friends and for Tony it is the gaining of his mother as a full time member of his household that up until now

just composed of him with his two children, Bella's grandchildren, dropping in from time to time.

Now, two years on, there has been some careful staff selection on Tony's part (for Bella to flourish staff would need to be both respectful of this intelligent, well educated woman and have the resilience to cope with bouts of confusion and anger). The creative thinking of this project and a commitment to what fits best for Bella and her family allows Bella to live between her own home and her "other home" with Tony. With the support of her now well known staff Bella moves and spends time between her two homes. This arrangement works well for both Bella and Tony. For Bella this has eased the constant pining she felt for her "own place" and for Tony it provides a time for renewal.

This story highlights that if we are prepared in our efforts to settle for something that might be less than optimal, then the people we support have no choice but to settle for it too. As in Bella's situation, a person

... it is
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centred approach becomes an authentic commitment to getting things right in the lives of people, person by person, and then we begin to come to an understanding of the struggle.

What we have learned:

In our attempt to develop a service that has its beginnings with the person it is seeking to serve, it would appear that there are three key factors that must be confronted.

1. You can't use the old entity and the old way to succeed with an approach that centres on the person. Professional dominance of a service will always mean that the voice of the people to be served will be weak. Within our project we are continually required to defend the voice of the older person and their family. This is not because the people in the system are bad, but because their belief in their professional rightness is so strong.

2. There must be a genuine commitment to and understanding of how to work in partnership with people. This is an essential element of individualisation

Where partnership is not authentic and rigid prescriptive top down methods emerge, this tells people there is a way to do things and they have to be done this way. These approaches, often dictated or determined by contract terms, lead to situations where people feel that they can't respond adaptively to people's lives.

3. We must have the right people in the right positions. The right people at the right time are essential, if we don't have the right people we won't get person centredness. You can't serve people if those supporting them are not creative thinkers and active problem solvers.

We need to give people more leeway on the methods available to them to achieve the desired outcome. Person Centredness requires people to struggle with the question of what would be better: This requires strong leadership that is determinedly committed to struggle with this question.

Factors that help

1) Design services one at a time:

We have been able to achieve genuinely individual options because we have been able to begin from scratch, with no preconceived options, no buildings, no staff, no programmes. This has enabled us to do something different with each person:

2) Flexibility of models and methods

We were able to start with the premise that the older person and their family would guide us in what makes sense for their lives and that the model of service

provided would be one that best addressed the needs of the person and their family. This has enabled everything essentially to be negotiable.

3) A vision of what is possible.

We have been able to defend a position that older people will thrive best when they are supported to remain as closely connected to their place, their roles, their positions and relationships as possible.

4) Willingness to experiment.

We have managed to resist the pressure, both internal and external to making risk aversion a priority of service. We give serious attention to managing individual vulnerability and this has given us the freedom to bend the rules and to experiment with what might work best in any given situation.

5) Defence

We have come to recognise that a person centred service of this type needs to be consistently defended. We continually need to explain the nature of the service being provided and to defend its continued investment. This is likely to always be the case when what is being provided challenges the accepted wisdom and pushes the boundaries of people's vested interests.

6) The need to stay small and closely connected to the people being served.

This is the challenge of being large enough to be able to sustain the service but small enough to remain deeply faithful to the people being supported.

7) Understanding the importance of seeking to meet the universal or "ordinary" needs of the people first. Clearly the particular support needs people have are important in the development and delivery of a service. Giving precedence to these particular needs can make it too easy to overlook those essential human needs that makes a person's life worth living. When we focus on what makes the person different the service becomes more important than the person's life.

The value in being guided by the realities of people's lives cannot be underestimated. If people's actual well being is used as the key litmus test of a change initiative, it enables change to be grounded in the presence or absence of this well being. When change is not tested against people's lives, then there is always the danger that it will be abstract and ideological with potentially unforeseen consequences for those impacted by the change. This initiative has helped clarify how much better it is when people are supported in their autonomy, so that the changes that do come about arise from their active involvement in the decision-making. By design, in this instance, it is principally the person who is influencing the changes in their lives, not an agency or a system prescribing solutions from a distance.

Changing the perception of People with Disability in the Work force

Linda Rolfe is Director of the Division of Developmental Disabilities in Washington State. She has worked in the field of developmental disabilities for over 40 years. In her career Linda has been a PASS and PASSING Team Leader and Workshop Coordinator. She presided over the development of guidelines for Washington State service providers. She also presided over the development and implementation of the Working Age Adult Policy in Washington that establishes the expectation that all people with disabilities can be employed and have the right and responsibility to be employed. Linda has consulted with several states as well as nationally on employment issues for people with disabilities.

People with severe disabilities in Washington State are working because they expected to have jobs, someone in their family expected them to have jobs, and the system that they rely on expects and delivers work.

To achieve consistent employment options for people with disability Linda Rolfe describes the five elements she believes are required:

TO BELIEVE IT IS TO SEE IT

Systems that provide supports to people with disabilities have a primary responsibility to foster and support high expectations for typical lives, typical work, typical experiences and typical relationships. Most disability systems in the USA have mission statements that reflect support for valued lives, dignity and respect and train staff to these values. In most cases systems in the USA work toward small-individualized living arrangements with the value being participation in and use of community resources. Based on these values, governments in the United States have closed or greatly reduced reliance on large congregate living environments.

However, while working toward smaller individualized living environments and increasing supports to families to keep family members home, government has continued to support congregate day activity centers for people with the most severe disabilities and sheltered workshops to house people with less severe disabilities during daytime hours. The primary reasons for people participating in these kinds of environments is the belief that these people cannot possibly be part of the typical workforce; that no business would hire

someone with this level of disability and for some the misguided sense that people with disabilities should not be forced to work.

What is missing is the belief that people can work and can be a valued resource. Any system, service or agency that purports to support people with disabilities must expect working age people to work regardless of their disability. No individual should be arbitrarily written off. Every person deserves high expectations. Every person deserves a chance to be valued for what he or she can deliver in the work place. Every person has the right to be evaluated against what value he or she can bring to the work place and deliver to the company's bottom line.

Most working age people with disabilities do not work; not because they can't but because work is not expected and work is not delivered. If we believe that all people deserve a chance to be a valued part of community, then we must believe in all of the people we support and deliver to them the opportunity to work in and for that community.

CAPACITY

An employment system that succeeds in delivering jobs to people with severe disabilities is a union of expectation and accomplishment. Much of our history reinforces attitudes that lead to low expectations. Media attention frequently evokes sensationalism and pity. People with disabilities are not expected to have real lives let alone real jobs. Most of society still believes that institutionalization is a good option and that people should be with people who are like them. Managing expectations is essential to creating opportunity for people to work. We must believe that people with disabilities

can enter the workforce and should have jobs to create that reality.

Washington State started its journey toward full employment for people with disabilities in the mid 1970s. We started with value based training for all employees. At the same time we created an annual conference targeted at celebrating the state's commitment to provide the support necessary for people with severe disabilities to work. Washington also scoured the nation for experts committed to work as a viable option and for employment agencies that were making work happen. As more people began to believe employment was possible, more people expected it and as more people expected employment, successful results were achieved. At least some of the people who got good jobs in the beginning days of Washington's employment initiative today are retiring from those jobs with pretty decent retirement packages. We published our success stories. Today you can visit <http://peopleworking.wikispaces.com> to continue to read about people with severe disabilities that have good jobs in Washington State.

Whenever employment agencies were successful at locating jobs and making successful placements, their expertise and experience was documented and offered to other agencies in the state on a shared success plan. Employment agencies that developed specific expertise in operations, marketing, employer development, individual career development planning were identified and supported to provide consulting expertise to other employment agencies who needed support in that particular skill. Every part of the state had one or more employment agencies that were noted for specific expertise and identified experts in the employment process. We also convened leaders at least annually to discuss good, better and best practice and revive our commitment to the expectation and the reality of good jobs for all people with disabilities.

We built on success and success changed what we expected and what we could tolerate. It also changed what we could deliver. It became clear that when we had resources Washington could reliably and consistently place people with severe intellectual impairments and people with severe physical impairments in good jobs. The record for placing people with both severe intellectual and severe physical impairments is not reliable and not consistent. It is a record we must change. We know we can because we have succeeded in employment options for some individuals just not at the numbers or the work hours level that would indicate quality or success.

Most working
age people with
disabilities do not
work; not because
they can't but
because work is not
expected and work
is not delivered.

To date individual employment agencies have been responsible for finding and training competent employment specialists. To achieve full employment for people with disabilities it is important to have a steady stream of qualified competent employment specialists. Washington has developed and implemented a nine-month course to certify graduates capable of supporting career planning, marketing, job development, employer development, precision teaching, and job coaching.

Another key to capacity is that schools must ensure that the transition curriculum in High School carries the expectation that the student, regardless of disability, will work at the end of her/his school career or will matriculate to further education like vocational/technical school or college/university. Besides the expectation of employment, schools must craft curricula that include strategies to ensure a smooth transition to work. Some of those strategies may include paid employment experiences while in school, a career development plan, a work experience portfolio demonstrating the kinds of skills the student has. Leveraging the funds spent on students with disabilities in their high school experience to prepare them more adequately for work in adulthood makes real fiscal sense.

ALLIES/SHARED LEADERSHIP

Finding the people and the entities who share the vision of real lives and real jobs is critical to establishing the leadership that will achieve the goal. It is essential to commit to the belief that working age people have a right and responsibility to work. There are many who fail to believe that real lives and real jobs are possible for people with the most severe disabilities.

Self advocates are the greatest allies. For the most part people with disabilities in the United States live in poverty and almost always qualify for monthly government cheques. The organised self advocate movement has as part of their mission statement the importance of the right to work and the right to be recognised for personal contributions. Self advocates' voices are essential to the why of work. Only they can describe the personal difference between having a job and not having a job. Self advocates can personally describe what it means to them to escape poverty.

Families may also be allies. Families whose networks often find jobs for sons and daughters without disabilities with practical support can help find the right job fit for their sons and daughters with disabilities. Every system achievement including real jobs in real industry with good wages and benefits, has depended on the leadership of families. If offered reasonable support and opportunity, families that have led the fight for inclusion of their sons and daughters in education, in community and in friendships with others will encourage their sons and daughters to work.

"I like my coworkers and my boss - they are really nice to me. They help me and it is a fun place to work." Sarah became acquainted with REI clothing shop through the LWSO Transition Academy, which helped her get an unpaid internship at the store. She was successful, and the next summer, King County Developmental Disability Division's School to Work program allowed her to work at REI again, this time in a paid internship. In September of 2007, Leslie at REI interviewed and hired Sarah in a regular part time job. Sarah has progressed from cleaning the changing rooms and tidying up the store to working in merchandizing. She helps unpack new merchandise, and sometimes brings items out onto the floor.

"Her coworkers at REI are absolutely fabulous," says her mother Diana Arnold. "They said, 'We know what to do. We can handle this.' They have coffee with her, have taken her under their wing, invite her to company events, had a birthday party for her, and have really welcomed her. Their positive energy has rubbed off on Sarah. They help her at work, and keep adding new things for her to do." Sarah is supported on the job by her coworkers, and has help and training support available when needed from April at Eastside Employment Services. <http://peopleworking.wikispaces.com/Sarah+at+REI>

Current employment providers may be allies. For example some sheltered workshops have made values and business decisions to transform into individual employment agencies. They believe that the people they support can be part of the regular workforce. Employment agencies have hundreds of examples of successful job placements that have transformed peoples' lives. Employment agencies have data to support that their business model is cost effective as well as producing quality deliverables for their clients. They have stories and data that demonstrate that firstly hiring people with disabilities is good business and secondly that good jobs bring people out of poverty. Jobs can give families cost effective options when their sons and daughters leave school. Employment agencies specializing in finding jobs for people with severe disabilities have won over business and industry by focusing on employer needs. They refuse to approach the task as resolving a human service need and instead focus on the employer need that their potential worker can meet.

Business may be allies. There are 2000+ businesses in Washington State that have seen a positive effect by hiring people with disabilities; people that are willing to work hard and are grateful for the chance to be part of the company. These businesses have participated in affirmative hiring practices that evaluate the work they need done and match the skills of the available workforce so that people with disabilities have opportunities.

Unions may be allies. Having a stable reliable workforce is good for everyone. Enlightened union leadership can promote a full employment agenda. All union members regardless of disability pay dues.

Finally some of the most important allies in building systems that support real lives and real jobs are people or entities who stand in your way. Find a way to make them partners. They can be key to a successful outcome.

SYSTEMIC SUPPORT

Government recognises the importance of work. Most government policies in the United States from education to economic security to health and human services recognize the importance of work to all citizens but in particular to citizens with disabilities. Working age people with disabilities without a steady source of income are often able to rely on government for economic, physical and emotional health. It is cost effective for government to promote policies that enable people with disabilities to work.

The first most promising asset for systems that value employment in the United States is the educational system. Schools that develop curricula that encourage and assist students to graduate/transition with jobs or with job experience portfolios allow employment systems to stretch resources to cover more people because the school system has already helped the student make a solid connection to work as well as create the expectation for work.

Other government programs in the United States include options that help the person keep government medical coverage while working; or to count some earnings toward the cost of their care so that government benefits may be retained. These incentives allow people with significant disabilities to work without risking their health or welfare.

Government programs that do not promote employment for working age people expend resources on day activities for an average of 50 years after the person leaves school. Government programs that do promote employment result in meaningful wages and greater independence. In Washington State the data that is available demonstrates that fewer state resources are expended in the long term for individuals with developmental disabilities that have stable employment.

QUALITY – DATA DRIVEN

Different from residential services, employment has immediate trackable outcomes that are consistent with how typical workforce indicators are measured. It is difficult to measure quality of relationships, recreation activities, time spent doing chores, grocery shopping or all the other myriad activities of living life because so much depends on personal preference and there are many choices. There are, however, readily available common measures for employment including minimum wage or better and an 8-hour/5 day week; health and other benefits.

Committing to employment as the preferred option for working-age people means committing to measuring the impact of employment by reporting on the outcomes achieved; how much people earn; how much they work; what benefits they get.

Successful systems measure and report on results. Every state in the United States has a generic system that monitors and reports on jobs, wages and benefits at the individual worker level. Even if a specialised system does report on jobs, wages and benefits, an agreement with the generic system can provide an accurate and valid check. Data can be a useful tool to assist with planning and decision-making. It is important to collect and use it wisely.

For most people in society, work is a highly valued way of achieving income, status, satisfaction and connection to the people in the community. As well as the economic benefit, it is a way to form friendships and develop relationships. Our contribution to society is given value through our work and we are seen as contributing citizens. For many people with disability this opportunity has not been possible. The stories of people with disability working in Washington State are a powerful example of how strong leadership and a belief in change made this a reality. It serves as an example of a way forward for other communities working towards inclusion of people with disability in the workforce.

Raising consciousness and influencing positive change through Developmental Evaluation

Standards and Monitoring Services (SAMS) is a Charitable Trust, based in New Zealand, governed by persons with a disability and families. 80% of SAMS trained and experienced evaluators are people with disability or family members and SAMS conducts approximately 100 service evaluations each year. SAMS has conducted evaluations for thirty years.

Mark Benjamin has worked in a variety of Human Services and is the current Chief Executive of SAMS. Mark has conducted developmental evaluations, for SAMS, over the last twenty years.

Developmental evaluation can be an effective catalyst for positive change. Developmental evaluation demonstrates processes likely to cultivate innovation while providing a frame of reference for growth. With organisations and administrations seeking tools for effective service transformation there has been an explosion of interest in evaluation. Developmental evaluation is intended to assist services to improve and is firmly grounded in collaborative and inclusive approaches. The most certain and sustainable form of development is founded on increased awareness and partnership. Together, raised consciousness combined with thoughtful action can birth service transformation. In 2009, SAMS celebrated 30 years of conducting developmental evaluation. This has provided an opportunity to reflect on approaches most likely to increase consciousness and the practices associated with successful developmental evaluation.

Evaluation can be experienced as helpful in the creation and maintenance of quality services or an invasion, hindrance or distraction. This article describes how SAMS developmental evaluation can enable service users and families to assume a leading role in service improvement, increase perception and be an effective catalyst for sustained progress.

The territory of evaluation has become clouded with the advent of evaluation approaches that are more akin to “compliance audit”. Audit approaches tend to use the language of quality but are essentially committed to ascertaining the existence of deficit and paper based procedures. Some evaluation approaches have removed the “human” from Human Services and compromised the value of evaluation. This is demonstrated in approaches that do not gather opinions from the key people associated with services (individuals who use the service, family or personal networks and staff in direct service provision) and are prescriptive in nature.

Such approaches seek to assure compliance to minimum standards and are founded on a belief that standardisation equates to quality.

The justification for evaluation is that it enables people to obtain better lives. The primary focus of SAMS developmental evaluation is to influence positive change, raise consciousness and cultivate innovation. The usefulness of evaluation is directly reflected in its ability (or not) to contribute to the development of services that facilitate increased quality of life for individuals, families and communities. A byproduct (sub-component) of the evaluation process is gathering information related to the degree to which legislative and contractual obligations are met.

In 1994, SAMS developed the Multi-Perspective Approach (MPA)¹ to developmental evaluation. The Multi-Perspective Approach (MPA) primarily uses qualitative methods and a partnership model. The methodology is consistent with principles of individual focus, partnership, inclusion and equity. The SAMS MPA enables both a process and outcome focus allowing the evaluation team to equitably represent the different views of defined groups, and compare the outcomes for the differing groups.

To successfully raise consciousness there are a number of key evaluation principles and practices. These practices contribute to creating an environment more likely to result in successful developmental evaluation. These are summarised as follows:

- Ensuring evaluation practice is built on the foundation of clear values and principles e.g. full participation of people with disability and families in key roles
- Clarity of intent i.e. development not compliance\

¹ Benjamin, M., Capie, A.C.M., and Nossin, M. (1998). *Measuring the Quality of Community Services*. Wellington, NZ: Standards and Monitoring Services.

- Awareness that an important aspect of developmental evaluation is cultivating innovation i.e. preparing an environment that is likely to result in people discovering new (and hopefully better) ways of doing things e.g. building inclusive and trusting partnerships, blank page thinking, discovering allies (not creating adversaries) and promoting accountability in a no blame environment.
- Ensuring organisational integrity e.g. to increase credibility it is important to demonstrate that you, as an evaluation organisation, are practicing the things you will evaluate others on e.g. partnership
- Understanding organisational and personal development i.e. the key is constructive movement not compliance or perfection
- Appropriate outcome based frameworks
- Flexible, fair, constructive and inclusive processes
- Approaches that are culturally appropriate

When the culture and practice of evaluation is based on optimism, inclusion and equity then an environment is created where evaluation can be a medium to raise consciousness within services.

Developmental Evaluation – A Consciousness Raising Strategy

Over the last three decades, SAMS has observed many approaches that claim to result in service transformation. SAMS has found that having people with disability and families, as core contributors to Developmental Evaluation, places the people with the greatest “vested interest” in a position of authority and influence. Consciousness is raised by the composition of an evaluation team and their contribution as well as the content of the evaluation. When the integrity of developmental evaluation is intact then it can have a wide ranging impact.

The process of consciousness raising is woven throughout the Developmental Evaluation approach. SAMS has discovered that the most effective approach to increasing awareness, and contributing to positive change, is to create a relaxed, personal and informal environment. Discussions and conversations replace interviews and participants are invited (not expected) to engage.

Consciousness raising can be applied to the following:

Attitudes

Inviting organisations to demonstrate how their existing processes and practices are a reflection of their stated values provides another forum for increasing awareness. Alternatively, organisations can be gently encouraged to identify and explain actual values that may be revealed in their existing practices. Both approaches invite people to raise their consciousness by naming existing and desirable values. By being explicit in this process organisations learn or refine skills relevant to examining and establishing congruency.

Ensuring evaluation teams include people with disability and/or families, creating equitable input into the evaluation process, the thoughtful use of language and a consistent focus on optimistic approaches demonstrate many desired values and attitudes. People participating in the evaluation are surrounded by behaviours that reflect a set of explicit values and are led to reflect more deeply on their own values. Indicators of these actual values are varied e.g. language, the degree of authority held by service users

or who is assumed to need the greatest input to an evaluation process.

Awareness of our attitudes and values gives an opportunity to explore what defines our world and motivates us. The cycle of attitudes determining behaviours that then reinforce our attitudes can be transformed into a growth spiral when we are more intentional in choosing our values.

Aspirations

As the evaluation process unfolds the individual’s stated aspirations are then matched with the inevitable paperwork created by the organisation e.g. person centred plans. This is then matched with where staff focus and resources are placed. This enables service users and staff to examine whether individual aspiration is indeed determining service delivery. Clearly this process either becomes self affirming or naturally highlights areas for further exploration and development.

Matching the organisation’s strategic plans and

The justification for evaluation is that it enables people to obtain better lives.

business plans with the expressed preferences and aspirations of service users then allows consideration of who actually has power in the system. Obtaining the perspectives of direct support staff assists evaluators, and the organisation, to deliver effectiveness in facilitating service users to achieve their aspirations.

Potential

Developmental evaluation is focused on assisting services to effectively support people to experience a great life. Consistent attention is needed to “what is a great life?” and “how are individuals being supported to obtain a great life?” Results in increased awareness of potential. Evaluation processes routinely surface previously unrecognised potentials for service users and encourages staff to recognise opportunities that have previously been obscured. Considering the restricted and oppressive conditions many have lived in and the sometimes limited environments staff have worked in, being able to conceive of new possibilities can be a considerable, but exciting, challenge.

Priorities

Examining the things individuals, families, staff and organisations choose to prioritise is a fundamental building block to raising consciousness. Thoughtful attention to what is perceived as “most important” can be lost in the day to day operation of a service. Developmental evaluation highlights which priorities are determining the shape and practice of a service.

Processes

Rather than attention to the detail of protocols and procedures, developmental evaluation promotes an increased attentiveness to process. In this context “process” refers to a series of steps that are taken to achieve a desired outcome. A process is a journey where the destination is anticipated but not always certain. Increased consciousness involves attention to the steps individuals or organisations are taking and where they may lead. Developmental evaluation assists organisations to determine whether existing processes are effective or consistent with where people want to go.

Healthy developmental evaluation processes demonstrate inclusion, partnership, flexibility, constructiveness and a willingness to negotiate. Therefore, participation in evaluation brings people into contact with the processes evaluation is seeking to affirm or create in services.

Practices

On an individual level, in the Human Services, “practice” is the action and interaction that relates to what we are actually doing. Developmental evaluation provides an opportunity to explore whether what is actually done is consistent with stated values and the processes endorsed or required by an organisation. Examining what is done – in the light of preference, expectation and desirability – is a powerful catalyst for increased awareness.

Developmental evaluation can be a catalyst and support for raising consciousness as it enables individuals and organisations to:

1. Paying attention (sharpening sensitivity to the environment in which we operate interactions and the outcomes associated with our practices)
2. Taking responsibility (acknowledges and owns the impact we have)
3. Seeking new knowledge
4. Committing to change
5. Discovering and creating allies

Raising consciousness is a precursor to positive change that has integrity and the potential to endure. Development based on increased awareness is more durable because it is a genuine reflection of changed perception and priority. Externally imposed change is fragile as it did not emanate from the individuals themselves. It is likely to last until the next external force impacts.

Developmental evaluation creates an environment to optimise the opportunity for raised consciousness. Individuals involved in developmental evaluation are likely to involve themselves in processes that significantly increase the chance of genuine insight. In an era where many seek someone else’s recipe for a good service, developmental evaluation invites individuals and organisations to discover their own strengths, aspirations, opportunities, assets and potentials. Developmental evaluation can assist by mapping the territory that can be explored and suggest some tracks that can be taken.

Developmental evaluation assists service users, families, staff and management to create great lives and communities.

A longer version of this article is available by contacting Community Resource Unit (CRU).