

Community-Based Support for People with Mental Health Disabilities: What Makes a Difference?

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“We don’t make changes to people’s lives we assist people to make their own changes.”

UnitingCare Wesley Port Adelaide is now a significant provider of *non-clinical services* particularly housing, support for living independently, employment and recreation programs. This paper has been written based on the advice of staff and Consumers of UnitingCare Wesley Port Adelaide’s various programs for people with disabilities resulting from Mental Illness who are seeking to live fulfilled lives in the community. Its perspective is that of a non-clinical approach but also acknowledges the fundamental importance of clinicians and other players within the Mental Health system.

Various staff and Consumers were asked ‘What makes a difference?’ In summary their responses were:

1. There needs to be a clear acceptance of *the status of the Consumer as the principal goal setter*, player and evaluator.
2. *A positive relationship aimed at independence.*
3. There must be agreement and clear expectations as to the *roles of the Consumer, community support worker, key worker and other players.*
4. *Incentives and practicalities should be consistent with the Consumer’s goal* (not serving the needs of the Agency or Government).
5. *Staff need an underpinning structure* to maintain their enthusiasm and clarity of focus.
6. *A professional, responsive Mental Health System* with skilled clinicians and other staff as fundamental to community based services as to more traditional Hospital programs.

1. Clear Status of the Consumer as the principal goal setter

“Consumer focus” means that the Consumer sets the goals, the pace and, in the end, accepts responsibility for what happens. This is not a passive but an interactive process with goals/actions/outcomes being a major topic of discussion but, in the end, the Consumer decides and accepts the outcomes. Examples of this can be seen from several quotes from Consumers;

- “My aim to have assistance in seeking a new home was accepted.”
- “They would listen to any adjustment to the plan I wanted.”
- “Final decisions are mine.”

This is what we mean by ‘client choice’. Obviously we are all restricted in our choices by our make-up and the circumstances of our lives but we grow and achieve when we make good choices and are successful in achieving our objectives. The more they are *our* choices and *our* actions, the more we grow in confidence and self esteem and in the ability to tackle further goals and tasks.

It is important to note that, although we, the Service Provider, have a “duty of care” to our consumers we do not have the ultimate right to protect people from their own choices and life experiences. In the end we all learn from our experiences even though they may at times be painful.

It is helpful to *encourage Consumers to dream*: One of our staff said “Talk about dreams no matter how unrealistic they may seem at first, find what these dreams mean to the person and start looking for ways to move towards the realisation of these dreams. Dreams are the driving force, they get people beyond what seems achievable. Do not say no, say lets explore and see what happens.” Part of our role is to structure the journey towards the dream with steps that may be more achievable.

- One man, for example, wanted to set up his own business, a difficult endeavour in a competitive world. His dream was accepted as the long-term goal and he was encouraged to explore all aspects and to take steps to develop the relevant knowledge and skills including planning, budgeting, networking etc. Even though his dream is still some way in the future he has developed skills which he has utilised in various aspects of his life. He has changed his dream somewhat but it still provides a positive direction.
- Another man in his fifties had a dream of having his own home which seemed impossible after eight years in a boarding house. He has now moved into his own two bedroom unit (with Portway Housing Association), has established an immaculate garden, has neighbours as friends and is managing with minimal external supports.

Underlying our work is a belief that we all have *strengths and abilities* far above those we demonstrate and use. What people need is the opportunity to demonstrate those strengths and abilities and so reinforce their dignity and self esteem. Often the debilitating nature of mental illness and the way people are treated by the community reinforces a sense that mental illness pervades all aspects of the person’s life ignoring the fact that many parts of their lives are still intrinsically vibrant and alive. What makes a difference is opening a window to allow those strengths and abilities to be expressed. Together with the Consumer we are often fighting a pervasive sense of being disabled and the acceptance of a negative identity as the only secure understanding of one’s self. Focussing on abilities, providing positive reinforcement, acknowledgment and encouragement challenges this negativity and encourages self belief.

Initial and ongoing assessment emphasising people’s goals and strengths and abilities as well as their diagnosis of illness is a key to assisting clients to recognise and build on their strengths. Such assessment must open options for new opportunities to compliment the more derived or medical response and will often draw upon community support much broader than initially expected. For example a Consumer who was referred for help with household tasks and not initially interested in receiving support was encouraged to express his abilities as an artist. Much of his support was focussed on his artistic pursuits resulting in the holding of a public exhibition, which clearly demonstrated his talents and gave him a sense of achievement.

2. A positive relationship aimed at independence.

The relationship between the Community Support Worker and the consumer is crucial to achieving positive outcomes. There must be a comprehensive understanding of both the supporter and the supported to facilitate a successful matching including a preparedness to change the Community Support Worker or renegotiate our mutual expectations if appropriate. This matching is critical to success. We once placed a very thin worker with a woman who was fixated by her own size and could not believe that this worker was naturally thin. Consequently she wouldn’t let the worker into the house (a reflection of the clients failure to be slim I suppose) so we changed the worker. The more robust build of the replacement worker yielded far better results. Another example is that of the cricket crazy worker being matched with a cricket enthusiast client – this worked very well because, whilst the worker was referred for household tasks, the client began to do these prior to the worker appearing so that they could then go and play cricket! This client was supposed to be without domestic skills whatsoever!

Our experience confirms that a positive relationship between people is enhancing to the self esteem of both parties and can be in itself the basis of positive change. One of our staff said, “Sometimes people make huge changes in their lives with what appears to be little input from services. In these cases it is the power of simply having someone or knowing someone is there. This should never be underestimated. Sometimes by focussing on raising self esteem and self confidence people actually address the presenting issues in their lives themselves. They reclaim the skills that are being influenced by their disability. Really, we don’t make changes to peoples lives we assist people to make their own changes.”

To emphasise this we changed the title of our workers from Direct Care Worker to Community Support Worker. We felt that “Direct Care” may have implied “doing to others” where as we see our staff as supporting those taking as much responsibility for themselves as they can.

Consumers of our services aim to live independently in the community. This implies that they may need assistance to reconnect to friends, relatives, community groups etc. and that they are not helped in their aim by becoming dependent on their support worker. Several years ago a Consumer gave us telling feedback; when asked for her comment on the long term outcome of our involvement she said “my worker became my best friend but when she finished I had no friends!”

Assisting Consumers to connect to the community in a safe, enduring way is a key role for our workers. This may involve gaining new confidence, re-learning interpersonal skills, finding interesting activities and developing long term habits. In the end, sustained recovery depends largely on the ability of each person to find support and a sense of belonging in their community.

3. Clear Expectation of Roles

Any helping relationship works better when there are clear, shared expectations about, and mutual respect for, each person’s role; that is how each is expected to act and behave.

It is important to acknowledge that the Consumer is clearly the person “in the hot seat!” They are the one facing the challenges and with the work to do. The Community Support Worker is more like a *coach* who does not play the game directly but understands what is involved and encourages the player, thus increasing their chances of playing better than they otherwise might and in achieving their personal goals.

A good coach has the wisdom to know how to relate to each player individually; how far to challenge, when to back off, when to encourage and when to listen, provide feedback and enhance understanding of consequences of particular actions and directions. Good coaches learn from their players and use that learning to further refine their own understanding of what it takes to meet challenges and be successful. The coach is then more able to support others by passing on his/her learning.

Role modelling is a powerful tool. The coach should model the skills, attitude and behaviours most likely to lead to success and act in a manner consistent with their own advice. At all times the coach must respect the player, the team and all other key personnel.

One of the cornerstones of our program is the *Three Way Care Agreement* between the Consumer, the Community Support Worker and the Key Worker from Mental Health Services. This agreement sets out the rights of the Consumer and the agreed goals and clarifies what each is expected to do. It is reviewed regularly according to an agreed schedule and modified as the goals of, and challenges to, the Consumer change.

An individual Care Plan is put in place which highlights strategies and timeframes in which to complete the goal. This ensures clarity of purpose but also provides a focus at reviews of how each of the three parties involved have carried out their tasks. Consumers report that it moves support from being general to a focus on specific outcomes and helps them to know what to expect and where they stand with their care workers.

Part of the challenge to Service Providers is to promote real and effective *Consumer participation* to ensure the Consumer is genuinely listened to and involved. The care agreement is perhaps the most fundamental form of Consumer participation along with the nature of the relationship between the Community Support Worker and the Consumer on a day to day level. Both the program and Consumer, however, benefit from Consumers being involved in program planning and evaluation, staff selection and focussed reviews. We have developed a system within which Consumers are paid for their input in these roles (as are staff) since their views and experiences are critical in practice and policy development.

The Three Way Care Agreement is consistent with the *Recognition of all Stakeholders* which is another crucial aspect of a successful program. UnitingCare Wesley Port Adelaide runs non-clinical programs and works in collaboration and partnership with other players especially within the Mental Health system. Over the past few years the mutual respect between agencies and our ability to cooperate has grown such that a true sense of partnership now exists, especially between UnitingCare Wesley Port Adelaide and Mental Health staff. Other key stakeholders such as carers, housing providers, employers and General Practitioners must be part of a system of open communication with clear understanding of their role expectation.

As non-clinical workers our staff take the lead from Clinicians to ensure that we are a constructive part of the team supporting the Consumer. On the other hand, we believe that we play a significant role and expect to be taken seriously by clinical staff and that, through accountable practice, we have gained that level of credibility. Where all stakeholders work in concert the best outcomes are achieved. We have reached the stage where clinicians often invite our input into their assessment and planning since our staff are the people that spend most time with the Consumer.

4. Incentives and Practicalities

To be accepted into our programs a person must have the aim of living as independently as they can in the community. Our role is to support people in this which can be assisted by aligning incentives and practicalities with this goal.

When *UnitingCare* Wesley Port Adelaide took over management of the services now known as Metro Access, we were concerned that the program had within it disincentives to people to live as independently as some were able.

Consumers were mostly accommodated in group homes with support hours allocated to households rather than individuals. People who increased their ability to live independently faced the possibility of losing both their housing and their support (sometimes their best friend). When asked how they wanted to live, almost all chose to live by themselves (often in proximity to friends or relatives). Through a variety of Housing programs especially the Housing Trust and Housing Association, we have assisted almost all our consumers to become tenants in their own house. This meant that we were able to direct support to each individual as appropriate to their goals and abilities.

The practical matter of being in your own home, usually as a tenant, with clear privileges, rights and responsibilities gives people the incentive to maintain that home, improve their circumstances and be rewarded by the pride and security of having your own space. This adds to the culturally correct respect of staff asking permission to enter a Consumer's house etc. thus reinforcing the status of the Consumer as being a person who voluntarily invites our worker into their home, and indeed, their life.

This process established a separation of roles between landlord and support worker. The tenant has rights and responsibilities in respect to the landlord and the Community Support Worker will assist the Consumer to maintain the tenancy but will not have control over that part of the Consumer's life. Maintaining your tenancy is a key part of living independently in the community and is therefore often a significant focus of our work with Consumers. It can be a challenge to tenants and the incentive to develop and maintain skills and habits that are useful in all areas of community living eg. budgeting, house cleaning and maintaining reliable friends are key to maintaining your good relationship with your landlord but they also enhance your ability to sustain yourself in other aspects of your life.

For this system to work well, secure affordable housing is fundamental. It is the basis of a person's sense of security and must be maintained through any periods of hospitalisation that may occur.

A sense of ownership and pride in one's home is only possible if it is indeed "homely". This means that practical matters such as furniture, bedding, and curtains must be acquired to make the house liveable, reinforce a sense of pride, build on the excitement of gaining a house and turn it into your own home. Consumers enjoy being an active participant in the acquiring of these basics which they then own. This process confirms Consumers in their, sometimes new, status of being a successful, independent tenant with a positive future and a home worth maintaining.

Mental Illness can be episodic and with disabilities fluctuating from time to time. A practical matter that makes a big difference to our ability to respond to these changes is the availability of a pool of flexible support hours enabling our senior staff to quickly increase support for short periods of time prior to a renegotiation of the Care Agreement. Timely responses followed up consistently and more intensively for several weeks have proven to be an effective strategy in reducing the likelihood of a more serious re-admittance to hospital.

Celebration and recognition of our achievements are crucial to each of us as we self-consciously strive to cope with our self doubts. Each small step towards the broader goal can be a significant achievement and should be celebrated to reinforce the success and build confidence for future challenges. Small steps such as catching a bus for the first time in many years, attending a recreational activity in the community, cooking a special meal rather than eating take away or purchasing groceries in a large shopping centre can be significant indicators of success in moving towards a person's goal of living as independently as possible within the community. Although small in themselves they are an integral part of the fabric of our lives and when recognised by ourselves and others are the building blocks of enhanced self esteem and self confidence. Our staff pay particular attention to recognition and celebration of achievement involving verbal praise, celebratory lunches, letters of acknowledgement or formal meetings and the like.

5. Underpinning Structure for Staff and Program

The Agency plays a significant role in providing value based leadership, security and continuity of employment for staff and continuity for consumers if staff change. The agency also defines acceptable standards, promotes accountability and consistency across the program as well as ensuring that program wide evaluation occurs. Senior staff play an active role in resolving problems as they arise and in negotiating with other parties. They are also responsible for supporting workers in areas which may have implications for occupational health and safety.

In order to stay enthused, keep a clear focus and maintain a good sense of humour, staff need to be supported within an underpinning structure. Key aspects of the structure are clear, focussed leadership, careful attention to the recruitment of staff, ongoing staff training and development and professional supervision. Regular meetings focussing on peer support, sharing of experiences and problem solving enable workers to draw strength and learn from each other. This develops a culture in which staff feel valued and that they make a real contribution to the program and Consumers. It also helps workers resolve personal issues and emotions which come from working closely with people who may be expressing hurt and strong feelings.

Our staff work independently in the community, they use their initiative and are given a high level of trust and responsibility to carry out their work. Feedback from staff suggest that this, as well as supervision, training etc., encourages a high level of commitment to the Consumers and the organisation. This makes a real difference to the quality of service.

6. Professional, Responsive Mental Health System

This paper is written from the perspective of what makes a difference in non-clinical support for people to live independently in the community. This whole process is, however, predicated on the existence of a highly competent, professional Mental Health System that provides excellent clinical assessment and treatment, hospital care when appropriate, long term intensive clinical support and immediate intervention at times of crisis.

Our services depend on the Key Worker particularly members of the Continuing Care and Mobile Assertive Care Teams. Recognising the importance of the Clinical role, our staff contact Key Workers when significant deterioration in a Consumer's Mental Health is observed, for example a Consumer becomes more delusional, more agitated or stops taking medication. This is based on protocols established as part of the Three Way Care Agreement and have the consent of the Consumer.

With such a Mental Health System in place, non-clinical services have been proven to make a big difference to the ability of Mental Health Consumers to live fulfilled lives in the community.

Acknowledgements

This paper is written based on the comments of Consumers and Staff of the various community based programs for people with disabilities resulting from Mental Illness run by *UnitingCare* Wesley Port Adelaide. These programs include Metro Access, Metro Options, Neighbourhood Access, Metro Community Living, Employment Access, Portway Housing Association, and Chat and Chew.