Beyond Respite Care

“Designing Support Services for Individuals and Families in Ways That Enhance Life”

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The development and expansion of community support options for people living in our communities has been a positive influence on human service provision over the past 10 to 15 years. A major focus has been the rapid expansion of community based models that aim to provide support in the home or other community settings.

One of the drivers for the expansion of community based models has been the recognition that the vast majority of care in our community is already provided by family, friends and volunteers and not by paid service providers.

There is also recognition that it is entirely natural for families and friends to care for each other and this natural support within family networks should be supported by governments and service providers.

People and families want to stay together, they want to support each other and they want to be supported to do this for as long as it is appropriate.
Respite Care and other community support services are seen as one of the primary means of offering support to families and friends who are caring for people living in our community.

The growth of community based supports for people is also in recognition of the fact that people want to live in their community, stay in their own home, close to their family and friends.

Also, it is generally recognised that institutional models have failed to meet the life expectations of people who live in them and their families.

Other things that are driving the growth and development of community support services include, the increasing number of people in our community who need support, changing demographics, changes in the role governments around the world are playing as providers of support services to people etc (there are many more examples/reasons why this growth has occurred)
While this growth in community support options is positive in that more and more people are able to be supported in their own homes, enjoying an improved quality of life, not all developments in community service provision are congruent with the desire of most people to live their life without unnecessary interaction with systems and bureaucracies.

In fact, many initiatives in human service in recent years have had the (unintended) consequence of disempowering people and fracturing their connection to family, friends and community networks.

These systems place an over reliance on technologies that surround service, such as formalised standardised assessment, standardised individual planning and needs analysis, functionalised service delivery based on a predetermined menu of service outputs, standardised formulaic service allocation processes (everyone gets 10 hours per week).
Such systems are what could be called “Life Denying” systems, - that is they appear to operate in denial that the person served had a real life or has a right to a life beyond what the service systems allows.

Our collective aim should be to create services that are “life enhancing”.

The approach that Community Options has taken in attempting to serve our clients in life “enhancing” ways is based on the following principles:

1. Supports focus on strengthening and reflecting the usual or natural relationships around the person;

2. The voice of families and individuals in determining the type and nature of support is recognised and strengthened;

3. Supports reconnect people with their community, their activities and their lifestyles;
4. Supports are structured, planned and delivered in ways that are “user friendly”, and;

5. People and families are not be labelled through their interaction with the service system;

In expanding on these principles I will draw on examples from the entire spectrum of the Community Options’ client group and not just in relation to people caring for someone who is living with dementia.

1. Supports focus on strengthening and reflecting the usual or natural relationships around the person

By this I am suggesting that the purpose of providing services should be to allow the natural flow of the relationships that surround a person is maintained for as long as possible.
So rather than automatically seeking to segregate individuals from their families or networks people should be supported to do things that they would normally do together and also be supported to do those things that they would normally do apart.

Supports should be focussed on maintaining or enhancing the persons ability to live their life and to continue to participate in the life of those that are important to them.

So, for example, where a person is caring for a family member, say their parent, support should be conceived, planned and delivered in ways that primarily enhances the parent/child relationship and allows the parent and their child to do what children and parents usually do together, appropriate to their stage in life - and also what they would usually do apart from each other.

A practical example; - when a family wanted to travel interstate to attend a wedding. The first response was to seek a respite placement for the family member needing support – this person had very high
support needs and also displayed behaviour that could be described as
c Challenging. However, with careful planning and some thought,
support was arranged that allowed the family to take the person
needing care to the wedding. As a result the family had less stress and
worry, less guilt about leaving an important family member out of
such a major celebration and a real sense of surprise and pride that
they had included their family member in this happy event.

2. The voice of families and individuals in determining the type
and nature of supports provided is recognised and strengthened

Many people are surprised by the number of individuals and families
that are unhappy with the service they receive. The source of their
unhappiness, in a large number of occasions appears to centre around
two factors. Firstly, providers do not include the person or family in
basic decision making about the support they receive; and secondly,
the family or individual is expected to accept and be happy with,
standardised and “one size fits all” models of service.
A better approach is to allow families and individuals to have a high degree of say or to even take directive control over their services. By this, I mean, to have control or a significant say over who, what, when, where and how service is provided. It is also right that families and individuals have real options for meaningful negotiation with the service provider about all elements of the service, that is offered to the person.

There are two important concepts that should be incorporated into progressive service design. Firstly, our aim should be to develop “Right Relationship” between the service provider and the person and/or family being supported. “Right Relationship” is an ethical condition that exists between services and those they serve, when the people served are seen and treated with appropriate respect, integrity and value, and where they are enabled to be decisively influential in how they are to be assisted (Michael Kendrick) and;

Secondly, the degree to which individuals and families are able to exert influence over services they receive should be transparent. One
analysis of the various degrees of influence has been prepared by Michael Kendrick
(refer to slide)
Most services that achieve a true “right relationship” with the people they service will have reached at least level four on this scale.

3. Supports reconnect people with their community, their activities and their lifestyles

In this day of purchaser/provider models of funding and output based contracts there is a real tendency to functionalise service delivery. By this, I mean the tendency for service to be defined by units of outputs, for example, hours of respite care or personal care, number of meals delivered, or hours of housework. Additionally, the success of the service provider is measured against the volume of service delivered. Also most service standards focus on internal or management aspects of the service and not on the outcomes achieved for people.
The result of this is that service is often delivered without any consideration as to why it is being provided or what outcome we are trying to achieve through the delivery of support.

A better approach is to see the provision of support as a way to connect (or reconnect) the person and their family with their lives as members of the community.

To do this we need to recognise that people should have lives beyond the services they receive. And therefore service provision should have a purpose beyond the function it performs.

People who we serve should be seen as a whole person, not just defined by their disability, their diagnosis or by the services they receive.

An example to illustrate this point – there was a person who was receiving many hours of personal care and domestic assistance each week. This service was being provided in a very functionalised way and despite the level of support provided the person was feeling very
lonely and isolated. When asked what would make their life better the client revealed that they had not been able to get to church for three years and desperately wanted to go. On investigation it was revealed that members of the person’s church were willing and able to support the person when they attended, the barrier was the transport to and from church – the solution was to pay a $25 taxi fare once a week – the outcome was a person who was reconnected with a very important aspect of their life. A person, who is now happier, was able to re-establish friendships and who feels included and valued by her community.

Another example is a man living in a facility in 24 hour care – this man would like to be able to go to his local club occasionally and have a beer – despite the fact that many thousands of dollars are being spent providing personal care and other assistance to this person each year – this basic, normal every day need has not been met. So this person is bathed, dressed, has his teeth cleaned and hair brushed and is otherwise supported to sit in his house all day surrounded by paid staff. The support he receives, as extensive as it is, fails to meet his
basic desire to be connected and involved with his friends and community.

4. **Supports are structured, planned and delivered in ways that are “user friendly”**

When people and families come into contact with the service system they are often under pressure, feeling very stressed, tired and unsure about the future. It is therefore so important that their interaction with the system does not add to that stress but actually reduces it.

Services should take real steps to be user friendly. Services should see their role as serving the family or person. Needless assessment and reassessment should be avoided. Families and individuals should be trusted to know their own basic support needs. Service bureaucracy should be reduced and the families and individuals should be shielded from it as much as possible and should not have to deal with it at all.
Needless or repetitive filling in of forms or providing personal information should be avoided.

Most importantly, the people in service organisations who have contact with families and individuals should have the authority to make basic service delivery decisions and not always have to go back to the “office” to get approval.

Services should seek to develop a culture of saying “yes” more often, and asking “why not” instead of saying “no” to reasonable requests form individuals and families.

Services should aim to minimise rules and regulations and, from the individual and families viewpoint become a bureaucracy free zone.

5. People or families are not be labelled through their interaction with the service system

All providers should take active steps to stop the practice of labelling people and families that they support.
It is symptomatic of many of the issues I have tried to outline above that, for example, a couple can be married for fifty years and at some ill defined point they cease being husband and wife, and become a carer and a cared for person.

Or a parent of a child with a disability suddenly is no longer a parent, they become a carer.

Of course those are only the earliest and perhaps least harmful labels that may be applied to these people.

Others such as having challenging behaviour, being difficult, non-compliant, severely stressed, non-coping, ungrateful, uncaring, interfering, emotional, irrational and unreasonable are commonly used to describe people caring for others and the person they care for.

Often these labels are used when the person or family are just desperate for practical basic service.

An example of the uselessness and dangers of labelling can be seen in relation to a person that we know, who one group of professionals had
identified has having “challenging behaviour” and thereby denied access to respite care, yet another group of professionals identified the behaviour as a positive communication strategy.

All services should aim to maintain and strengthen the primary relationship between the person providing care and the person receiving care. This approach is essential if we are to maintain the basic human dignity and value of the people that we serve.

The five principles outlined in this presentation form the basis of all good human service design and should be incorporated into the basic building blocks of our community support services.

Thank you