CRUCIAL TIMES

Community Resource Unit Inc.
Level 2, 43 Peel Street, South Brisbane
P.O.Box 3722, South Brisbane Q 4101
Ph. 38442211 Fax: 38443400
www.cru.org.au

Getting the balance right – the blending of natural supports with paid supports

This edition of CRUcial Times will focus on the importance of carefully blending natural supports with paid supports as a strategy for enhancing the likelihood that people disability get to live the life they want. This is very pertinent at the moment as the National Disability Insurance Scheme (NDIS) begins in Australia, there is potential for more people to receive funded support than in the past.

If we look back over recent decades, generally the support of people with disability rested with their family. If a time came when families were no longer able to do that alone the only option was to hand the care of the person over to an organisation who then made the decisions and took charge of the person's life. This was not the case for everyone of course, but historically many people received either all informal support, provided by family OR all formal paid support, provided by workers and professionals, but not necessarily a useful combination of both.

As we move to the NDIS it is helpful to understand this history so that we don't just repeat or reinforce this traditional thinking. Instead, the hope would be that people with disabilities and families take up this opportunity to have a good life in community, supported by and capitalising on the best combination of both formal and informal supports.

The gradual introduction of individualised funding over recent years has highlighted the potential for the formal to usurp the informal and we see the cost of that in the loneliness and disconnection in many people's lives. Formal support may be very high quality and provided by caring, committed staff but if the person has no friends, little contact with family and is isolated from their neighbourhood and community, then the promise of individualised funding remains unfulfilled. If used well, funding, especially when it is individualised, can be extremely useful but it can't buy a life.

If we think about what happens for most people, the informal or ordinary are the main relationships in their lives and they are also supported and their lives are enhanced by formal or paid supports that they choose. To draw a simple parallel, I engage a dentist, plumber and electrician in paid formal capacities and the natural supporters I have are my extended family, friends and neighbours. While the first group are essential and play a critical part in the areas of my life I ask them to, it is the second group that are the most important to me, have known me longest and know me best. If I couldn't speak for myself it's them I would want to speak for me and make decisions on my behalf. It's my relationships with them that give my life meaning.

In the lives of people with disability, the importance and authority of each group

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Editorial Margaret Rodgers, Chief Executive Officer

can become confused, and we witness the experience and knowledge of family and friends becoming secondary to the contribution of the formal supporters. Without some careful thought, we also see relationships with friends and the opportunity to be part of the day-to-day rhythms of life replaced by specialised responses and supports, and people's lives are poorer for that move.

When natural, freely given support is not valued as the primary support but is relegated to second place, we see the practical contributions that the natural supporters offer being fitted into a person's week after the formal support is in place. Family and friends begin to be seen as unpaid support workers; filling the shifts that workers don't do rather than the reverse. Of course, some of this has happened for economic reasons or due to the rigidity of rules of the support on offer. However, when people have more say over their support our challenge is to ensure that thinking such as this doesn't carry across into the new possibilities.

In this edition, Michael Kendrick offers us ten guiding principles to consider as we harness and blend natural and paid supports. He reminds us that natural support should be the foundation of the arrangement so that the person remains embedded in community rather than becoming stranded or isolated within formal systems and isolated from community. The unique lifestyle of each person needs to remain the focus of any support.

The tendency for formal systems to usurp informal systems is not unique to the disability sector; but is important to safeguard against. Our writers share some practical strategies they have used. Lynne and Robert Walmsley describe how they think about the roles of various people who support Robert to achieve the things he wants. They also explain how they have invited some people to help them plan; how that network has grown and expanded over time, and how it works alongside the formal support that Robert receives.

In her article, Pam Termont-Schenk reflects on her son Jamon's move into his own home and shares with us what they have discovered as Jamon has been supported by family, friends and flatmates to achieve this. Pam talks of identifying some beacons that help guide and illuminate important philosophies they hold around Jamon's life. She is clear that Jamon has authority over his own life and that he needs assistance from family, friends and paid supporters to develop, nurture and live the life he chooses.

Sarah Scown shares with us her experience of providing formal support for a young woman who was establishing her place in the world. Sarah describes the progression as the young woman tried different things and her life evolved and therefore how the formal support also needed to evolve in response. If the person at the centre is unable to direct their life by themselves, then finding some way to ensure their supporters are working in unison towards a shared purpose and vision will be important. Sarah describes the shared planning processes and the ongoing communication required.

Adrienne McGhee has recently completed some study about the the knowledge of support workers and the importance of blending their knowledge with the knowledge of the person they are supporting to create a new way of working that does not situate the worker as expert. She also explores where the knowledge they bring comes from, what 'best' knowledge is, and the implications for supporting and resourcing workers with this.

I think that one of the biggest challenges we face is ensuring that the additional paid support that is on offer from the NDIS actually improves the quality of life of people with disability. If people take up more paid support without challenging our past thinking and habits and considering carefully where it fits in relation to their informal, freely given supports, then there is a great risk that the informal supports will be overpowered or overshadowed. When this happens, people with disability may have good and more plentiful formal support but they are unlikely to have the rich experience of living an ordinary life in community.

Margaret Rodgers

Chief Executive Officer

From the President

I thought I would start the process of writing this article by doing some research, so I started by googling formal and informal supports to see what kind of information was available that may offer me some insight to what I was going to write.

When I googled the topic I learned that formal and informal supports are good for the elderly, for those who have been victims of crime, they can be good for those recovering from drug use, they can be helpful if you are grieving and they can be utilised to support families of children with autism…wow! I think these articles that I found in Google really just show us how important the use of formal and informal supports are for a broad spectrum of people, especially those people that may need a bit more support.

Of course these are only examples of where someone has identified and documented situations wherein using formal and informal supports have proven successful. But after some more reflection I would say that we all use formal and informal supports everyday as part of an ordinary life. We just may not have had a need to identify it in such a way.

Formal supports are easy to identify as they are generally paid. Some we use as a matter of necessity such as the doctor. Some we use to make our lives easier, for example, paying a cleaner to save time and energy.

Informal supports are unpaid but their importance becomes clear in discussions about what adds quality to our lives. In my experience they help us build friendships and communities and become our lifeblood when life gets in a pickle.

It is how we blend these supports that I think can really add value to our lives. For example, if I am facing some sort of difficulty in my life then it might be appropriate for me to go and see a counsellor. That would be my formal support and probably a very important one if I need some extra support. As well as see my counsellor, I might choose to catch up with a friend and go for coffee and a chat (two other loves of mine) and that might also be really beneficial to help me work through some of my stresses. Furthermore, I might let my parents look after my kids for a few hours on the weekend so I can have some time to myself to relax in whatever way I choose. Friends and family networks are great informal supports.

Using terms like formal and informal supports are great but I think Google may have led me a little bit astray. Whilst they may be more readily associated with all those groups listed above, they are really just part of an ordinary life.

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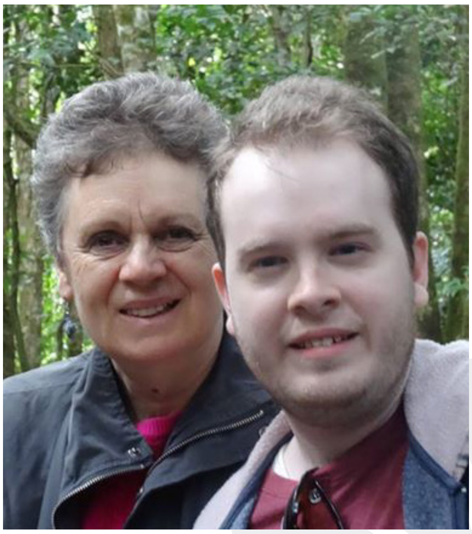
Getting to Balance

Lynn Walmsley

Lynn Walmsley is the mother of two adult sons and one adult step son, the youngest of whom, Robert, has several disabilities. Lynn's work experience prior to having her children included working in the disability sector. This experience led her to seek out parent advocacy organisations upon moving to Australia when the children were young, which then sparked Lynn's quest for inclusive education and inclusion in community for Robert. This article has been written with input from Robert Walmsley-Evans.



Getting to Balance

My son Robert is 23 years old. We have received some paid supports since he was three years old. In the past seven years we have become much more intentional in finding natural, unpaid supports amongst friends and family, as I am very conscious of the importance of these relationships for the longer term wellbeing of Robert.

Something I have discovered is that involvement of family and friends is much more prevalent than I used to think. Many of these people are those we have interacted with in other settings, often over long periods of time. One in particular has been our neighbour who we have known for over 20 years. We did not know her very well for a long time, but in recent years she has become an integral part of our lives.

When Robert was very young, the first paid supports we had were to enable him to have other people to interact with, and to assist Robert with exploring his creative skills such as writing and painting. This also freed up my time to keep our home running smoothly; at that time Robert required a lot of specialist appointments, attended therapy weekly and did daily exercise. Assistance at home helped me to do all that was needed to engage Robert successfully in all his endeavours.

Over the years we have refined our use of paid supports. Once Robert started attending school the week days were largely taken care of, therefore support workers were mainly assisting Robert with recreation, getting exercise, and completing his homework and projects. We always had an eye on inclusion in the community and we would have a paid support worker to assist with our social soccer group, every second Saturday. After the game, everyone would come back to our house for afternoon tea and the kids would run around.

While the circle members can help with planning and with making steps towards goals, paid supports are another important way of getting the goals on the Plan accomplished.

We took advantage of every opportunity for Robert to socialise with his peers and he is still friends today with several young men from preschool and primary school. As a family we take education very seriously, so during Robert's school years there was a great deal of input making sure he was getting the best possible education. Both support workers and family and friends contributed and helped us get through projects like how to bind a book or make a model of a Martian!

During the last couple of years of high school it was becoming very clear that things were about to change. Robert would need paid support to pursue his education (Cert III in Events Management at Tafe) and developing his skills in Photography and Writing.

After fifteen years of attending events on developing a 'Good Life' and five years on sessions about Circles of Support we decided to finally take action. We invited others to help us develop a vision and plan with Robert for his present and future. We embarked on forming a Circle of Support comprised of family and friends to assist us, with the help of a facilitator. Approaching people via our facilitator was very difficult for me initially. I knew we needed other people involved but didn't like to ask. To my surprise, the response was terrific. Several people on Robert's circle are past support workers who were with us when they were students. One of them lives in another city and keeps in touch when in town and via social media, another one lives just around the corner.

Many great suggestions have come out of the circle meetings. When we wondered about how Robert could enjoy more reading, a circle member suggested doing a letter box drop in the local area to see if someone who also loved reading similar subjects such as Philosophy, Shakespeare, Bill Bryson, Fantasy, and Classics, would like to read with Robert. Three weeks later we had a tap on the door; our neighbour Anne asked if we had had any success. She had been away and stated she "loves to read." She came to read with Robert for long stretches once per week and we have got to know her very well. It wasn't the original intention but Anne has become a great backup on occasions when paid support workers are late or can't make it. Another circle member had a contact in a café who agreed to Robert exhibiting some of his photos, and another member took Robert to another café and discussed with them the possibilities there.

The Plan therefore helps keep us very focused and guided as to what we ask for from potential support workers and where we need to engage family and friends more to ensure a rich life.

While the circle members can help with planning and with making steps towards goals, paid supports are another important way of getting the goals on the Plan accomplished. I will use Robert's interest in photography as an example; first he learnt skills in photography attending many courses to develop his knowledge and expertise. He entered both speciality and mainstream exhibitions including a project taking portraits of refugees - Refugrow - which was exhibited at City Hall. He has been included in the People's Choice of the Mayor's Annual Photography Exhibition and had his own landscape exhibition which he found very exciting. His photography endeavours have been supported by everyone including his support workers (they assist Robert to go out and take photos and upload them, and to attend a regular professional development group). Friends and family help to choose themes and which photos to exhibit and attending the launches and exhibitions. Thanks to intentional planning and the right supports Robert has developed his photographic skills to a high standard. Seeing the satisfaction of Robert having his own Photo Exhibition complete with launch and VIP's was priceless!

We continuously refer to the plan, and make sure Robert's goals are being attended to. It is vital that paid workers do not impinge on his family relationships and friendships. We make workers aware of the important key relationships in Robert's life so that they know to treat those relationships respectfully.

We do not use paid supports for things like going to the movies as we believe it is best for family and friends to enjoy movies and live events with him. Shopping with purpose (for a secret birthday gift for me!) or getting a haircut is acceptable, but not just going to the shops.

Family events take precedence and we rearrange things if necessary to accommodate. For example, if we can't fit in a request by a friend to take Robert out to fly a drone, we change the scheduled support. The flexibility of our self-directed support allows this to happen. Support via agencies is less flexible and therefore Robert has that mostly during the week when changes are less likely to be necessary and the routine is more predictable.

We have become more refined in our interviewing skills and expectations, so that if those expectations are not met after a few weeks we let those people go. Having the plan was a great step forward because if I feel pressure by a service to go down a path they want I say, "It's not on the plan." The Plan therefore helps keep us very focused and guided as to what we ask for from potential support workers and where we need to engage family and friends more to ensure a rich life.

Robert's plan for his life is big and expanding; as well as continuing photography Robert has plans for more travel, increasing his work hours, keeping in touch with old friends and developing new friends, attending university and publishing his novel. He will need the support of his family, friends and support workers so that his plans and dreams continue to be pursued successfully. Through intentional planning and the right balance of support Robert's future is bright and it belongs to him.

Principles for Partnering Between Natural and Formal Supporters Dr Michael Kendrick

Dr Michael Kendrick is well known internationally as an educator, advocate, consultant and author. He has worked in government and non-government agencies and consults on issues such as service quality, safeguards, and design of personalised services. He lives in the United States, but as a regular visitor to Queensland, he also understands the local and national issues that people with disability and their supporters face as they strive to live in their community.

A thoughtful combination of natural and formal supports can potentially enrich a person's wellbeing. 'Formal' supports are various forms of assistance provided to a person via paid formal services, professionals and agencies. Informal or 'natural' supports would include all of the many forms of everyday helpfulness and assistance ordinary people freely provide to each other in daily life.

There have commonly been instances in which this partnering was not beneficial. Some guiding principles may give us a better chance of reducing that risk and of producing more optimal results in partnering of this kind. Every person's life experience is unique, so being able to consider some universal principles such as the following enables interested people to carefully weigh what would be optimal for a given person.

1. The use of natural supports and formal supports are not necessarily mutually exclusive i.e. in principle both can be beneficially used at the same time and in conjunction with each other, though often for quite different purposes.
2. While formal and natural supports can, in principle, be blended into an overall individual support arrangement it is important to remember that 'one size does not fit all.' To be effective, they must be carefully combined with the needs and priorities of the person being paramount.
3. Both natural and formal supports are a means to an end and not an end in themselves. The proficient and beneficial combined use of natural and formal supports will arise from each being shaped to optimally address the person's wellbeing both singly and in concert with each other.
4. The goal of any combined support arrangement should not simply be to maintain a person's life as it is, but to mobilise these supports in engaging and addressing the ultimate potentials of the person, as there is always a real risk that such supports simply preserve 'what is' rather than 'what could be.'
5. The pursuit of intentionally 'imagining better' as a regular element of the building of 'what could be' in a person's life will generate the positive vision needed to guide both natural and formal supports.
6. If natural and formal supporters are to partner effectively and do not share common values, purposes and ethical obligations to the person being supported, they may work at cross purposes to each other rather than consciously unite their efforts in the ultimate interests of the person concerned.
7. When designing a given combined support arrangement, it is important that natural support be the foundation of the arrangement and that formal supports be secondary in order that the person concerned remain embedded first in community rather than have the person become stranded and isolated within formal systems and apart from community.
8. Given that every human being is conceivably a potential natural supporter and that formal supports are usually much less abundant and reliable than natural supports, it is better to rely on natural supports principally rather than on formal ones.
9. The person who is the focus of the potential partnering of formal and natural supports should, in concert with any chosen allies, ultimately govern the nature of the partnering, rather than be held hostage to priorities and agendas that are not their own.
10. Both natural and formal supports are subject to all of the inherent limitations and shortcomings of human beings and their efforts. It is important to intentionally reduce and offset these limits and shortcomings by safeguarding the quality of the partnership and therefore the benefits to the person.

Given that people's lives do not remain stable and are subject to all manner of potential changes, it is important that any such partnership take the time to regularly update and renew itself. One way to do so would be to return to these principles as guidance in refashioning the partnership should it be beneficial to do so.

Best Knowledge? Blending Knowledge in the Age of Person-Centred Support Adrienne McGhee

Adrienne McGhee has been involved in the disability sector in Queensland for 16 years, and has held a variety of roles including those of disability support worker, service manager, systems advocate, freelance consultant, sessional academic, friend and advocate. She recently completed a PhD about the knowledge of support workers who work with people ageing with an intellectual disability. Adrienne promotes the blending of a full range of 'evidences' into a unique knowledge that is built with and around each person in order to produce desired outcomes in his or her life.

Best Knowledge? Blending Knowledge in the Age of Person-Centred Support

Every human action is informed by knowledge. Swimming, singing, communicating and working are all possible because, at some point in our lives, we learned how to swim, sing, communicate and work. Even breathing is informed by intrinsic knowledge that is coded in our DNA and stored in our brain and bodies: we are able to breathe because of *knowledge that exists apart from thought*.

Knowledge is also at the heart of how we engage with and support people with a disability. It shapes how we interact with every individual and informs our ability to generate real-world outcomes in his or her life. Knowledge is, as such, a crucial consideration in our discussions about how disability support workers assist with the expansion of people's worlds, and the achievement of their goals and dreams for ordinary and fulfilled lives.

This article reflects on knowledge as it is used by disability support workers and as it may contribute to the shape of people's lives. It begins with a brief discussion about the past, often oppressive, impact of able-bodied knowledge on people with a disability and their supporters. It then highlights the importance of bringing together – or blending – relevant, important and valued sources of knowledge as a way of promoting responsive, proactive and person-centred supports in people's lives, and concludes with some implications about the use of blended knowledge for the learning and development of support workers in the future.

The rise, fall and rise of 'non-local experts'

Throughout history, the lives of people with a disability have been directed and dominated by those without disability: the able-bodied. The knowledge used to subjugate people with a disability has typically been shaped by the prevailing paradigm – or way of thinking – of the times, which today is positivism (also known as science).

Science has given birth to an array of experts – people who claim to have information and expertise about a particular area of knowledge and practice, and who agree to work within a clearly defined set of ethics and regulations. Within the contemporary disability field, experts include such groups as doctors, physiotherapists, psychiatrists, educators, psychologists, researchers and social workers.

Used humbly and appropriately, expert knowledge can be of considerable benefit to people with a disability: doctors can diagnose and treat life-threatening pneumonia; social workers can locate community-based resources and services, and assist people to successfully navigate complex bureaucracies; and speech therapists can teach people to communicate more effectively with a broader range of people. Scientific knowledge is a potentially powerful tool in the enhancement and expansion of people's lives.

Expert knowledge is not, however, always used to such positive ends. Historically, experts have often devalued the rich body of lived knowledge owned by the people themselves and the people who know them best, and instead reduced these individuals to objects on which they practice their profession. And while deinstitutionalisation brought a movement focused on restoring the ordinariness of life for people with a disability, in recent years managerialist approaches (such as quality and risk management) have resulted in a resurgence of expert knowledge in the form of 'evidence-based practice'. Evidence-based practice is supposed to be founded on the best available knowledge *as informed by experts and researchers.*

So despite growing rhetoric about person-centredness and self-direction, we increasingly find ourselves living in a world where the knowledge of 'distanced other' – the non-local experts – is valued more highly than that of *real people* with *real lives* living in *real places* who experience *real issues*.

Best knowledge in the real world

As a pracademic – someone who has one foot in the world of evidence-based knowledge and the other in real-world practice – I have struggled with the conundrum of what constitutes best knowledge in the lives of people with a disability for well over a decade. Having worked with and befriended many people with a disability during my time in this sector, I have often wondered what knowledge should inform our support to people with a disability, what best knowledge might look like, and how we should expect to see it reflected in people's lives.

During my PhD research in this area, I observed that the knowledge workers were using was considerably more complex in nature than had previously been discussed in the academic literature. As well as going to considerable lengths to incorporate the knowledge and perspectives of the people they supported (and, in many instances, their families and supporters), workers also drew on information learned during training; the regulations imposed upon them by their employers; their own personal, educational and professional backgrounds; the evidence-based knowledge held by professionals; and the internet to find opportunities, services and information that matched people's needs and circumstances. Workers' knowledge was, as such, made up of a vast and enmeshed blend of information, plans, values, strategies, approaches and actions that had been drawn from multiple places and people, and shaped into a form they used to respond to people's unique, real-life needs and priorities.

Blending knowledge

This drawing on, and blending of, multiple sources of knowledge was critical to the holistic support of the older people with an intellectual disability who were part of my study. Workers were supporting people with constantly changing needs, and were managing never-before-encountered issues as they journeyed deeper into the ageing process. For instance, workers increasingly found themselves supporting people with life-limiting illnesses such as dementia, Parkinson's disease, and cancer. They were also having to communicate concepts such as ageing, loss and death to individuals whose ability to fully comprehend abstract principles was unknown and often remained unknowable. Workers also struggled with organisational systems, policies and procedures that prevented people from having choice about how to live out their old age.

> **blending involved bringing together multiple sources of relevant and reputable knowledge into a highly targeted way of knowing about the person being supported.**

There was no single source of knowledge that workers could use to navigate their way through these (and other) challenges. People with a disability didn't have answers that could address all of the issues they faced. Parents didn't have answers that could address all the issues. Managers didn't have the answers. GPs and specialists didn't have answers. Palliative care professionals didn't have answers. Educators didn't have answers. In order to carve out a path through complexity and dilemma, workers sourced knowledge and advice from these and other relevant stakeholders, blended them into a way forward (using processes such as reflection, discussion and analysis), and were then guided in its implementation by the people themselves (and sometimes family members) and more experienced supervisors.

In the context of my study, blending involved bringing together multiple sources of relevant and reputable knowledge into a highly targeted way of knowing about the person being supported. It was shaped to suit who the person was, and his/her personal circumstances and unique needs, goals and dreams. The blending process can contribute to the growth of a practical knowledge – such as a plan, strategy, attitude, behaviour or approach – that could be used in partnership with the person to bring about desired outcomes in his or her life.[1]

Who supports the support workers? Implications for the growth of best knowledge

Our contemporary world is one where knowledge is produced at an exponential rate and is changing at a furious pace. No matter how dedicated we are to keeping up with advancements in health, developing strategies for improving social inclusion, or knowing our local communities, it is no longer possible to know and hold all the information we need for every activity we will undertake.

In the lives of people with a disability, we need workers who are focused on the goal of supporting people in ways that recognise, celebrate and respond to their uniqueness. We need workers who are committed to knowing better and more, and who are curious, courageous and creative in their pursuit of best knowledge. We also need workers who can use knowledge in ways that strengthen person-centred practice by finding it when it is needed, shaping it to suit circumstances, trialling it sensitively in people's lives, assessing its real-world value, and changing it to accommodate the ever-shifting landscape of life.

We also need to encourage workers to be this way. While our expectations for the highest standards of support should remain firm, we also need to recognise that workers' knowledge will – and should – always be in a state of flux, ready to adapt to the needs and preferences of the people they work with. As employers, we need to accept that it is challenging to work in a space where knowledge *is, and must always be, shifting if it is to remain best knowledge*. Well-intentioned mistakes will happen: it is how employers deal with them that will determine whether error becomes rich and deep learning that flows on into people's support.

Further, workers who diligently respond to the ever-changing needs, aspirations and lives of people with a disability will need opportunities to accumulate, to grow, and to shape their knowledge so they can offer relevant and effective supports that are aligned with who people are. We need to acknowledge the time, guidance and strategic thinking required by workers to build robust bodies of knowledge. If we fail to create opportunities for workers to build strong individualised knowledge around people, we will inevitably compromise the quality of people's support and the outcomes we strive for.

Finally, we also need to move away from the assumption that flooding workers with knowledge they may never use is the best way to support learning and development. In our world of information overload and complexity of lived experience, giving workers more information may not be as important as showing them how to manage and shape the many knowledges available to them into a form that fits people's lives.

We need to acknowledge the time, guidance and strategic thinking required by workers to build robust bodies of knowledge.

There is no replacement for knowledge that is grown out of real-world, lived experience. The fullest, most robust, support knowledge is, however, grown out of humble engagement with multiple sources of knowledge that are sensitively and sophisticatedly woven together into a tapestry that portrays the vibrant landscape of people's lives. Let's ensure disability workers are provided with well-thought-out foundations from which to grow a unique best knowledge around each person they support.

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[1] This process is one component of what I have called knowledge facilitation, a model of knowledge use for support workers that came out of my research. This model includes a number of concurrent processes that describe how workers can effectively use knowledge during support. These processes include: locating useful and appropriate sources of knowledge; evaluating their worth; synthesising – or blending – all of the high quality knowledge sources into a plan, strategy, attitude, behaviour or approach that can be actioned; using the knowledge alongside the person; reviewing whether the knowledge worked for the person and achieved his/her goal; and revising and refining it so that can contribute to better outcomes.

Re-imagining Supports: Creating the right blend. Sarah Scown

Sarah Scown has worked in the disability sector for almost twenty years. Starting her career as a Support Worker in large institutions in Canberra and in Brisbane highlighted for her the need to demand more from the sector. Over the past nine years, Sarah was involved with coordinating a small, local, not-for-profit disability service before working in her current role in case management for a Brisbane based NGO. In addition to her formal roles, Sarah has also been a member of a Circle of Support and sat on a Management Committee for a small disability service.

Re-imagining Supports: Creating the right blend.

I believe there is a place for paid roles in people's lives. We all access services for a range of reasons. I go to a dentist, mechanic, and use a telco. Typically we access these services knowing exactly what outcomes we expect from our interaction. Similarly, there is a role for human services to support people in areas defined by and expected by the individual.

As a person who has been privileged to have held a number and range of paid roles within the sector, my view of the role of a paid supporter is to stand beside an individual and (where appropriate) their family to help them achieve an ordinary, good life- whatever this may look like for each person. Anything is possible when people tap in to their passions and strengths and work creatively with these. Everyone has the potential and capacity to contribute in a meaningful way; it is about discovering a pathway based on what really excites and motivates each person, and then making sure they get the support they require, whether this is from family, friends or with assistance from paid supports.

My introduction to this way of thinking came when I started to work with a young woman, Melissa. Melissa had recently left school when I first met her, and she was living in a group home with two other people she and her family had not selected. Melissa was also attending a centre-based, post-school service. Her family quickly determined that despite lots of formal, paid support, she was not experiencing purpose, enrichment or relationships in either of these group environments and they set about seeking change.

Melissa's family were very driven to see their daughter happy and in an environment where she could succeed in safety. It was not a quick or easy process; however Melissa's family made two significant changes. Firstly they switched service providers and found a support model that enabled their daughter to live on her own in a privately rented home, with support staff of their choosing. I became Melissa's primary support worker in her new home. Although there was an overarching hosting organisation, I considered my direct employers to be Melissa and her parents. It was a very exciting time in Melissa's life.

After making the decision to use the post-school funding in a different way, Melissa and her family and friends met to develop primary goals to work on. These people were Melissa's parents, brother, a past school teacher and a family friend. After discussion and refining ideas, it basically came down to a fairly simple notion. Melissa and her family really wanted two things: friends and paid employment. So my role then extended to include both support in the home and support to find a meaningful way for Melissa to spend her work days.

We began this journey by brainstorming all the things that Melissa enjoyed in life. This list was long, but other than family and friends, it was noted that nothing excited her more than dogs. We were a good match in that regard and this was a deliberate act on behalf of her family. We were at a similar age and stage in life. Melissa's family felt this was more appropriate than having mum and dad directly involved.

Initially Melissa volunteered at the local animal shelter, taking the dogs for a walk. While Melissa enjoyed this role initially, she found it upsetting to contemplate the future if the dogs did not find homes.

She changed tack and started fundraising for the shelter instead to help the dogs in a different way. However, there was not a lot of direct contact with the dogs so another change was needed.

Next Melissa tried starting a dog walking business. She was known to many within the community and quickly generated some clientele after posting flyers, word of mouth and advertising through a contact she had on the local radio station. However, a few months in to the business, it became apparent that Melissa much preferred to cuddle and play with the dogs rather than walk them- which was wonderful for the dogs, but not the service for which the owners had paid.

It was again time for the circle to re-think what form Melissa's passion for dogs could take. There was a lot of brainstorming with people who knew her well and were keen to see her succeed. While ideas were still being generated, an offer came from the small, local vet practice who were looking for a volunteer to perform minor cleaning duties, in addition to offering companionship and affection to the animals in care. The practice had heard that Melissa was seeking a role with animals through word of mouth.

This was the right role for Melissa. She and her new workplace were a good match. She was happy with the direct contact with animals and she also liked having colleagues.

We really wanted to make this offer work. Initially it took time and intentional effort to ensure that Melissa's workplace saw her as their new employee, rather than identifying and developing a relationship with me. My role was necessary to help the workplace understand Melissa's intricate communication style and what additional needs she may have within the workplace, yet it also felt that there was a risk.

I needed to model an interaction style that was appropriate for the workplace, rather than our usual, more familiar style so that co-workers could follow my lead without having to rely on having an established relationship. While the workplace was still learning Melissa's communication methods, I made sure to refer all questions and instructions from Melissa's colleagues back to Melissa. Even if I ended up answering on her behalf, I made certain she was included and consulted in the process.

In order to resource her colleagues well, we were unfortunately accentuating her difference, so we kept daily visits short and positive while everyone was getting to know each other and these visits grew longer on a very gradual basis. It was important during this period to ensure that Melissa participated and contributed towards any special workplace events such as fundraising morning teas or staff birthday celebrations within the workplace.

Lastly, although it was a very small staff team, we noticed which staff were more inclined to have the time and the attitude to support Melissa in ongoing ways, and would offer to assist them with parts of their roles in order to further develop relationship.

It was again time for the circle to re-think what form Melissa's passion for dogs could take. There was a lot of brainstorming with people who knew her well and were keen to see her succeed.

Melissa and her supporters used her formal, paid support intentionaly, purely to assist with achieving specific parts of Melissa's vision.

Melissa eventually became a paid employee and a valuable member of the workplace, joining her co-workers for many of their social events and thus continued to build her personal networks. In addition to the relationships that developed, this role also generated an income and provided Melissa with meaningful purpose to each day whilst simultaneously celebrating her passions and talents.

Melissa's story highlighted for me the distinction between the role of informal and formal supports in a person's life. The people on Melissa's circle gave their time and energy freely. These people were not professionals or experts, they were ordinary folk who had developed relationships with Melissa over the years and who had a genuine interest to see her succeed and realise her potential. Melissa and her supporters used her formal, paid support intentionaly, purely to assist with achieving specific parts of Melissa's vision.

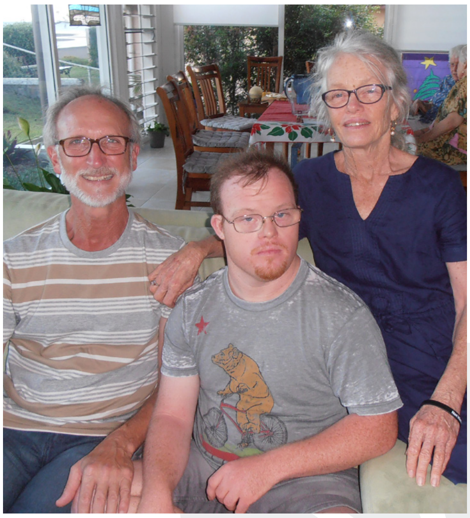
Melissa developed new levels of independence and learned many new skills through having a job but importantly she developed new relationships and friendships which brought meaning and joy to her life but interestingly, also reduced some of her need for formal support.

Over the two year period that I have described, I could see that the combination of informal and formal supports really worked for Melissa and helped her achieve some of the happiness, engagement and purpose that she had been seeking.

There Comes a Time in Every Young Man's Life

Pam Termont-Schenk

The Termont-Schenk family live in a small coastal community north of Brisbane. They have been involved in the disability world for 33 years and have always been strong advocates for all people being immersed in their local and world communities. They were instrumental in starting a cooperative in their local region; are active members of the Queensland Folk Federation; Woodford Folk Festival and Woodfordia Treehuggers as well as Zonta and Brotherhood of the Wordless. In this article Pam shares her experience of what they have learnt over the past 8 years since Jamon moved into his own home. Jamon, a keen artist and weatherman, is supported by his family, flatmate, friends and support workers. Jamon believes that it is important to give back and loves his life.
His thoughts on this are reflected in the quotes accompanying Pam's article.



There Comes a Time in Every Young Man's Life

There comes a time in every young man's life when he's gotta leave home whether it's by his own motivation or not. For some young men that decision is easier and for others a lot harder. Our son Jamon made it quite clear (mostly through his behaviour) a couple of years after finishing high school that, like his older sister and good friends, he would like to move out of home and make the transition to adulthood.

The leaving home process varies from person to person. For Jamon the planning was purposeful, intentional, not done alone, and was a process that lasted about three years. Planning didn't come without apprehension, fears, tears and a clear vision for Jamon to be an integral part of our family, his neighbourhood and his community. To live his life of choice we always knew that Jamon would need paid support to supplement the natural support of his family, friends and wider community. In our hearts we also knew that he liked people and would want to share his flat and that he really needed the safeguard of another person living with him.

Steve and I got to a stage where we realised that we didn't have all the questions, much less the answers, to help Jamon to achieve his goal. When it came to Jamon moving into a home of his own we felt we needed a more formal structure around him. We also needed that same structure to support us to help Jamon come up with the direction and guidance he needed in his life. So we formed Jamon's Support Network.

I like having my own place to do what I please. It's very important to me.

Jamon has been in his own home for eight years now. These years have given us the time to identify some beacons that help guide and illuminate important philosophies we hold around Jamon's life. Jamon has authority of his own life and we are here to assist him to develop, nurture and live the life he chooses. Jamon needs assistance from his family, friends and paid support worker to help maintain and develop relationships. It is important to maintain a natural blend of the people in Jamon's life and that everyone works together in a respectful and supportive relationship.

Life sharing is what we all do when we marry, move in with our partners and move out of the family home, so why would it be different for Jay? He longs for real connection with people. He often talks about his friends, past support workers and family. Jamon's flyers and adverts when searching for a new flatmate say things like "are you looking for something in your life beyond a share house? To truly connect and share life with those you live with?" This lets potential flatmates know from the start that this isn't the ordinary flatmate situation.

We find it is a balancing act on how to make the process of finding a new flatmate a natural thing when prospective people are being screened by the person's parents first. Yet the reality is that this natural family support is a required constant in Jamon's life. We also inform them that he has paid support workers in his life daily which means that those people come and go in the house under his and our direction to assist him to live his life.

When Jamon was living in a bungalow at our house and his support workers were coming into our home environment we experienced firsthand what it is like when someone comes into your personal living space. This helped us to communicate how to manoeuvre the awkwardness, interruption, pleasant exchanges, and unexpectedness that occurs for Jamon as well as for the informal and formal supports in his life when they connect.

Jamon also has a list of questions he asks in a second interview. He is very up front that if the person doesn't like open windows or getting up early in the morning it might not work out! He also acknowledges that their needs are important and it needs to be a respectful, two-sided relationship in the house when it comes to windows being open or closed, TV or music volume or what is being watched on TV or DVDs. Ultimately the decision of which flatmate to choose is up to Jamon; he has the last say.

Jamon's flatmate has an ordinary relationship with Jamon with some additional responsibilities. Flatmates know what Jamon expects of them; things like trust (which he explains and goes into detail about what that looks like for him); to live here freely as a companion and friend and not be in a more formal paid or volunteer role; and to have a genuine desire to live with him and assist him to share life with family and friends. In exchange for basically living rent free but sharing all the normal expenses of day to day living, Jamon's flatmate is expected to be sleeping at the flat overnight Sunday through Thursday nights unless we are notified so we can make other arrangements. We understand they have their own lives and we are willing to make adjustments in our life to accommodate that.

Jamon wants his flatmate to make his home their home as well. They have done this by bringing along their own families, friends, animals, plants, and household items. The development of life sharing is slow and Jamon allows new flatmates to arrive at that place in their own time and comfort. Each flatmate has established their own individual relationship with Jamon, his family and friends and his paid support workers. Jamon's present flatmate is taking on the life sharing qualities naturally. The guys go off nearly every morning for a walk and to do a circuit training session at a nearby park and then enjoy breakfast together. Occasionally on a Sunday afternoon our family will cook dinner together at Jamon's flat and his flatmate will join us if he is home. We have gone on hikes together, to theatre nights or musicals and for walks on the beach.

> ***I love having a housemate. I enjoy living with my current housemate the most. There are no bad bits. I like doing things together.***

Somewhere along the way we realised that the concept of life sharing also includes the people that are in the paid, formal roles in Jamon's life. Life is really an interdependence of all our lives as we mix and mingle in whatever role we might have at the moment and with whomever we are with. For example, we have encouraged support workers over the years to bring their children (babies, toddlers, young kids) to work on occasion if needed so Jamon gets experience with young children. This has been wonderful as it now translates for him into our own family. One of Jamon's support workers and his flatmate share a keen interest in fish. So Jamon's house went from having his one small tank he's kept for years to several more plus one huge tank.

Jamon's formal supports are in the role of paid support workers and there are some priorities that they are paid to keep upmost in their work. The relationship with Jamon's flat mate has a priority. They are there to support Jamon's connections and involvements in natural networks in his life. This includes how they interact when spontaneous events happen in Jamon's life such as when a friend passes by for a visit and they are there working, or family wants to go to dinner with Jamon that night when they are 'rostered', or someone invites him out for the night. Workers know their place which does not mean taking on a subservient role. On the contrary they will be asked their opinions and/or advice – in this context the relationship is a 'partnership.' In other situations like when friends come for dinner, paid staff will need to assume a less prominent role by paying attention to things like not getting too involved in conversation. We emphasise to Jay's workers that the flatmate is not in a paid role or volunteer role. The level and manner that the flatmate chooses to be involved in Jamon's life is up to them and they are not to be relied upon for information or treated as a worker. All workers are to be working in a relationship with Jamon's family and friends that involves mutual respect, humanness, individuality, honesty, openness, trust, and modesty.

Jamon says he is keen for all people involved in his life to contribute to thinking about aspects that will enrich his life but, as he puts it, he has 'two different worlds.' He sees both these worlds as important to living his life and that they need to connect.

As parents, our challenge to help Jamon to maintain and develop relationships remains at the top of our priority list. We reinforce to all people involved in Jamon's life that he is the one who has difficulty developing and maintaining relationships. He is the common link that brought them together and he would like to maintain that connection. When it comes to the involvement of people in Jamon's life we'd prefer that they do what comes naturally for them. However, we have learned that some people want or need more purposeful or formal invitations in place to maintain their involvement.

A common comment from both flatmates and support workers as they leave their roles is that they have felt fortunate to have been brought together with Jamon, his family, his friends and others. They say they have learned so much about themselves along the way. In being with Jamon they have been taught about their own humanity and humility, their own personal failings and inhibitions, their capacities and weaknesses. The depth of the experience can be life changing for Jamon and his flatmate, workers and their children. We are pleased that Jamon is doing his bit to raise the next generation with compassion, understanding, knowledge and experience.

> ***It is ok for my support workers to have a friendship with my housemates and it is ok for my paid support workers and housemates to bring friends and family to the house.***

NEW WEBSITE COMING SOON Launching in February 2016

Bringing the good life to life

CRU is pleased to announce we are in the final stages of developing our new website. This is designed to resource people to bring the good life to life for people with disability.

This new resource will be helpful to people as they prepare for the roll out of the National Disability Insurance Scheme (NDIS) in Australia. One page is dedicated to making the link between this initiative and the opportunity it provides to make life better for people.

This website will contain a broad selection of articles, videos and ideas drawn from CRU's existing resources and 20 new short films made for the purpose. It also has lots of interesting content from around Australia and the world.

The website contains 8 pages that cover the following topics:

- **The Good Life**
- **Getting Started**
- **Including Others**
- **The Role of the NDIS**
- **Important Partners**
- **Blocks and Barriers**
- **Keeping on Going**
- **The Bigger Picture**

Community Resource Unit Inc.

Claiming a Positive Future: the power of possibility.

CRU 2016 CONFERENCE

BRISBANE CONVENTION
& EXHIBITION CENTRE

20-21 MAY 2016

Community Resource Unit Inc. invites you to join us for our conference in Brisbane on the 20th and 21st May 2016.

We will gather with the aim of inspiring, encouraging and connecting people with disabilities, family members, friends and workers to focus on what is possible for all people who live with disability. We are interested in what this means across the whole age range from young children to mature adults.

Conference overview

As the National Disability Insurance Scheme starts to roll out in Australia, this conference will address how we can be clear, hopeful and focused, in order to make the most of this opportunity. As well, it will help us examine what gets in the way or diminishes what's possible and together explore new ideas for creating the change we want to see.

The conference will offer:

- local stories illustrating hopeful possibilities;
- interstate and international presenters sharing stories and helpful insights;
- time to connect with old friends and meet new ones.

Topics will include:

- Self-Determination
- Respectful Support
- Building Belonging
- Inclusion in School
- Working together for change
- The changing role of the paid supporters

Registrations now open

Speakers include:

Dr. SAM SMITH is the founder and CEO of C-Change Scotland, a not for profit organisation supporting people with disability to live the lives they choose. She also writes and campaigns on issues of equality and social justice.

C-Change Scotland was established in 2001 to support adults with disabilities or mental health issues who had significant reputations for challenging services. It has been at the forefront of providing personalised support with and for disabled people.

KATE McGINNITY from Wisconsin, is an experienced teacher, presenter, and author as well as a nationally recognized consultant in the field of autism. She has over 30 years experience working with individuals with autism and their families.

She currently provides training and consultation/coaching to professionals and parents as well as counseling and yoga to individuals on the autism spectrum.

EMMA GEE is one of Australia's acclaimed Inspirational Speakers. With a background in Occupational Therapy and as a Stroke Survivor, Emma is a living example of what it takes to step in another's shoes. She is passionate about enhancing personcentred service delivery and promoting resilience no matter what one's life experience.

DAN HABIB is a renowned photo journalist who became an advocate for inclusive education after the birth of his son Samuel in 2000. He is a member of Barack Obama's committee for people with intellectual disabilities.

Dan will be joining us via Skype from Concord, New Hampshire

More speakers to be announced shortly

For more information or to purchase tickets, go to: www.cru.org.au

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