

## Editorial: Building better lives - the role of formal support

In the 16th century the Polish astronomer Nicolaus Copernicus put forward a radical theory. He argued that, despite what people thought they were seeing, the planets were orbiting the sun rather than the earth and that the earth was just another planet. For the past thirteen hundred years everyone had 'known' that the earth was the centre of the universe and that the sun, moon and stars had all revolved around it. His declaration challenged the foundations of how people saw the world and their place in it.

Working to ensure that people with disability and families take their place at the centre of our universe, with the service delivery systems revolving around them, may be a modern day equivalent of the Copernican revolution. This paradigm shift requires us all to let go of long held beliefs and practices that had service systems firmly established at the centre and people and their families in orbit around them. Transitioning to the NDIS has the potential to be a revolutionary and fundamental change in how we think about support and a sizeable shift will be required from us all to achieve it, no matter where we fit in the universe.

In this edition of CRUCIAL Times, you will find illustrations and discussion on what support can look like when it is being offered well. At the heart of the messages in this edition is the notion of working one person at a time; to listen to and discern what each person really wants and needs and then to work with the person to assist them to achieve this. Our five writers, a number of whom require daily support due to disability, all speak of the need for reliability, respect and dignity and support tailored to what they need. This daily support is a means to an end not an end in itself. This is not very different to what any citizen expects when they engage a professional formally for expertise or support.

As the number of people directing and managing their support increases, it is not surprising that people report when support is targeted to their needs it increases their satisfaction and motivation as well as the efficiency and effectiveness of the support. Research also indicates that staff employed in such systems are more satisfied and generally stay longer.

It is not complicated, however we have a long history of thinking that because people with disabilities need some things to be different or special, we respond to all of their everyday human needs with things that are different or special. This thinking gets in the road of supporters listening to the person and appreciating the power of the typical response for all of us.

As things change and people with disability and families have more choice and control we would be naive to think that all power imbalances will suddenly be realigned. Paradigm shifts like this take time and thoughtful analysis and a willingness to change from all parties.

Former Canadian activist, Judith Snow points out that when formal supporters understand the person's goals and aspirations, as well as their needs, they play an invaluable role in assisting the person to take their place in their community. When the foundations of support are well provided then people can get on with life; go to school, university, and work or go out with friends. In her article

Sharon Bourke discusses the needs of the person with disability being central but not at the cost of respect for and valuing of the worker and their role. Sharon talks about the importance of collaboration and shares many practical points from her experience of assisting her son to manage his own supports.

Working "with" people and using common sense, honesty and good ethics is critical for both parties. If power is to be shared appropriately both parties also need to be reliable, trustworthy and reasonable in their requests and understanding of the consequences of their directions. This will help in establishing a culture of mutual respect which is a vital element of working together for a shared purpose.

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It's about negotiation. Relying on assumptions about who does what and the boundaries of that can lead to confusion, frustration and the erosion of relationships. Clarifying what tasks and responsibilities will remain as private (or family business) and what would be taken on by the organisation is simple but very important. These discussions and negotiations need to be held regularly and having a written agreement that sets negotiated boundaries for authority and its delegation is also very helpful. This can be generated by either party and one doesn't need to wait for the other.

Karin Swift recommends investing in the development of support workers. She advises that spending time sharing information with them and maintaining an open dialogue is critical. Setting aside resources in the budget for this is generally considered money well spent. When contrasted with the difficulty many people have of negotiating to get basic support needs met or spending the day waiting for someone to arrive this proactive negotiation seems preferable.

Our writers describe their feelings when support is not provided in a helpful way. Their examples speak clearly of how critical the role of the worker is in their lives and is instructive for everyone who offers support. Karin Swift talks about how shift changes that were out of her control, resulted in a hairy weekend at her house. Emma Gee, who has both provided support and received support, writes a very moving description of the difference that particular staff made to her recovery, even that 'she slept better at night' knowing certain people were there looking after her.

The challenge for people with disability as they take on more control, particularly those in the employer role is to respect their staff and the contribution they are making; to be very clear about what is non-negotiable, when to compromise, what is possible and what just can't be done. Obviously, not everything in service arrangements is negotiable. While core personal decisions need to stay with the person themselves, there will be some legal or service requirements that need to stay with the provider or worker.

The challenge for services is that in addition to the personal response, there are systemic shifts required to enable this way of working. These personal stories are situated within a continuum of systems. On one end are services that relate to each person as unique, and design and operate their service accordingly while at the other end work to serve the needs of the system first. Even though this will present a challenge, it is clear systems that are both flexible and designed by and with individuals are more likely to satisfy the people being served.

We see some practices in the delivery of formal supports that have been created in response to scarce resources or the rigidity of rules of the support on offer. For example, we see the practical contributions that the natural supporters offer being fitted into a person's week after the formal support is in place. This results in natural, freely given support not being as valued as they primary support but relegated to second place. Family and friends being to see themselves and be seen as unpaid support workers; filling the shifts that workers don't do rather than the reverse. As people have more say over their support arrangements, our challenge is to ensure that outdated and unhelpful thinking doesn't translate across into the new possibilities.

As in pre-Copernican society, our human service agency system has had some difficulty getting its relationships with its service recipients in proper order.



Sue Duncan-Kemp, a very experienced professional, reflects on how she has adjusted her thinking over time to understand how her skills and expertise can best contribute to the life the person wants, rather than take over or become too narrowly focused on one aspect of a person's life.

A view shared by all of our contributors is that workers and professionals can bring lots of valuable expertise, skills, experience and an outside perspective. The challenge is to share that with the person without taking away their personal authority. This involves letting go of the belief that the experts know better than the person themselves about how they should live their lives.

You won't find a formula within these pages for how to provide good quality support, but there is lots of shared wisdom and experience on where to start and what might be useful to consider. These articles illustrate that with thoughtful collaboration and negotiation people with disabilities can have a good life in community, supported by and capitalising on the best combination of formal, informal and mainstream supports.

**Margaret Rodgers**  
Chief Executive Officer



## From the Board

My first role as a support worker was in 2008 supporting adults to develop their skills and participate in their community through a day service. One of my key roles was facilitating song writing workshops, which lead to supporting people to have their voices heard by banks and politicians, but also by family and friends. I took my direction from the service and the people fitted into our programs, with some ability to help shape the programs.

Between 2011 and 2014, I worked for several other organisations in similar roles, and during this time I started to think more about what good support looks like – both for me and the people I was working with. In 2014, I began studying inclusion and this gave me an understanding of how disability has been perceived throughout history, and how this impacts on the present day. It was here that I was introduced to the theory of Social Role Valorisation (SRV) which would influence my understanding of support considerably.

In 2015, while completing my studies, I began supporting a man who manages his own supports with the help of his parents. This experience brought home how intentional one must be to ensure that support is working towards inclusion and the development of the person. I began to really think about the language that I was using as a support worker and I recognised afresh how my role could influence the life of the person that I was supporting. By developing a greater understanding of how the person felt, I could work alongside the person to break down the barriers that exist between society and its perception of disability.

In 2016, I began working part time as a development worker with a small, family governed organisation. In this role, I take my direction from each person and their family and it is an ongoing conversation about how to assist people to direct their support. This has again changed and increased significantly my understanding of what good support looks like.

This role as a development worker has helped me to see the role of support worker with fresh eyes. Looking back over the last nine years, I see clearly now that my role as a support worker was also to support people to develop and that has been a two-way street. As we learn and grow together, the relationship of support offers growth to both of us as people and not just the one.

**Luke O'Sullivan**  
Director

*In this role, I take my direction from each person and their family and it is an ongoing conversation about how to assist people to direct their support.*



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# Good support requires collaboration: unique design for a Good Life. Sharon Bourke

**Sharon Bourke** lives in regional Queensland and is the mother of three children, two of whom have lived with disability. In this article Sharon shares insights learned and developed with her son Dan. She discusses how people with disability and their families work to increase the chances that quality support is provided in an enduring way.

Sharon has worked in various roles in the sector, including managing support agencies, facilitating workshops and planning with families. She is committed to supporting individualised and quality support options for people with disability and their families.

## Good support requires collaboration: unique design for a Good Life.

After three years of Dan and directing and managing his support, I am now in the process of passing more responsibility over to him. As we reflect on what is important for him to know, we both have come to understand that managing support staff is not just about handling the paperwork. We all mature at our own rate growing our skills and relationships along the way. Constructing a good life and working collaboratively is a complex and messy business.

We learn and grow in relation to other people and the experiences which we share. We experience the joys and sadness of life buoyed and supported by those people we hold dear.

We have found that working together in partnership, with the right people for the job, in right relationship, creates the fertile ground for establishing a good life for Dan. This requires deep listening and understanding Dan's needs, while being creative when navigating the messiness of life.

Dan is a 28 year old man who is a song writer, larrikin and requires support staff because of the complexities of his physical disability. Dan is also the boss of those support staff. With some assistance from me, this five person crew works collaboratively to make sure that Dan's life continues in the direction that he defines as a good life. Relationships are at the heart of Dan's life. Strong and sustainable relationships over time will keep him safe as this will mean he has loved ones to share his joys and difficulties.

***Relationships are at the heart of Dan's life. Strong and sustainable relationships over time will keep him safe as this will mean he has loved ones to share his joys and difficulties.***



### Finding the right people

Life is messy and we expect that people who come to support Dan also live ordinary lives with all the messiness that involves. We seek people who not only understand the importance of relationships in the pursuit of a good life but who understand their part in fostering and encouraging friendships and connections for Dan.

The ability to maintain and grow relationships is essential. Dan learns through connecting with his networks but also learns from the process of connecting. Whilst being friendly and the role of connector is important, it should not be confused with being "paid friends". Dan has formed friendships in many ways and through different circumstances and sharing interests and passions. Sometimes, the invisible magic of friendship happens. Sometimes, people have come to Dan's life as a worker but stay beyond any paid role.

Dan and I employ staff together. We each have our roles during the initial interview, throughout training and in an ongoing way. We are their employers with Dan having final choice of his staff. As he matures, he is starting to take the lead.

There have been times when we sought to find perfect people to provide “good support” for Dan but they overlooked the joyful chaos of life and the ordinariness of relationships. We believe that when we pay for supports and services, we should expect the highest quality. For us this means staff who strive to learn and grow, believe in Dan, listen deeply and have sound practices so they truly assist HIM in HIS pursuit of a good life.

### **Right relationship**

Dan and I both agree that ALL people should be valued and respected. Living in “right relationship” is a guiding principle for living and working that reflects this belief; it is a way of being and thinking.

For us this means, mutual respect, responsibility, clear and honest communication, and learning from and with each other. It means forgiving the small stuff and striving to do better.

Right relationship is evidenced in the way Dan lives and interacts with staff, friends, family and members of his neighbourhood and community. Although it may seem that this is a lofty ideal, it also acknowledges the humanness of the experiences as everyone strives not to be perfect but to do the best they can, admit their mistakes and continue to work together as respectfully as possible.

To that aim, then, we approach recruiting, training and ongoing support of staff in a manner and practice that fits with “right relationship”. Dan is learning to be a fair boss and a decent person to his staff. With his staff and mentors he is learning how to navigate everyday life and how his support staff and mentors can best support his goals.

### **Clarity of the role**

In the past, we have struggled with not wanting to be too demanding for fear of deterring possible candidates. Experience has shown us that if we are clear and approach recruiting with honesty and respect, with an accurate job description and guidelines about how to support Dan successfully, it is much fairer on everyone. In fact, it reduces people’s anxiety and leads to a more open and honest relationship. People know what is expected of them, what training and support they will receive and what is not useful. As the saying goes, good fences make good neighbours.

*If we all set up good work conditions and try to keep the unexpected to a minimum, it is a great recipe for healthy work relationships. When unusual circumstances arise we find staff respond more flexibly because they don't feel taken for granted.*

*“We each have our roles during the initial interview, throughout training and in an ongoing way. We are their employers with Dan having final choice of his staff. As he matures, he is starting to take the lead”*

Support staff are interviewed by us and if chosen senior staff support them until they are confident. Support and follow up continues to ensure that the staff and Dan are confident with the quality of the support being provided. We have developed a checklist to keep this on track.

### **Appreciation for the humanness of the person**

A good life includes a life where staff have job satisfaction and feel valued. We foster open communication and we have learnt that the best results for Dan arise when people he employs are comfortable admitting to mistakes, asking for guidance and asking questions. We strive to give staff adequate work at times that are suitable and doing work for which they are well matched.

We make sure that there is enough staff to cover times of sickness and holidays or family leave. Too much overtime and unscheduled workloads adds pressures for staff and can impact negatively on their own families and relationships. If we all set up good work conditions and try to keep the unexpected to a minimum, it is a great recipe for healthy work relationships. When unusual circumstances arise we find staff respond more flexibly because they don't feel taken for granted.

## Training for strengths of the person and the parameters of the job

High quality support often depends on employing the right person for the job. We have found through our experience when we employ people with expertise, interest or passion in line with Dan's goals, we can offer staff job satisfaction. Dan has very distinct interests and when the right people are connected they contribute creative ideas and energy which brings mutual advantages.

The training which we offer is specific to Dan's needs and his preferences. Dan is actively engaged in training of his staff and whilst Dan's communication is complex, he is very clear about how he wants things done. Together with his family, senior staff have developed an extra written resource that explains in specific details what they have learned over time working collaboratively with Dan.

## Appreciation of a job well done

We have found that people enjoy their work when it fits with their interests, where they feel confident and comfortable in their work skills and responsibilities. This is why it is important that people's efforts and opinions are acknowledged and appreciated. Staff are given time to come together with us and we make it our everyday practice to thank staff and give positive feedback as appropriate. At the end of each day, we catch up in person where possible. Regular/daily conversations open the way for issues to be resolved as they arise and often before things become problematic.

## Collaboration

Dan now works with a senior worker to roster staff and plan for his week as well as some of the boring stuff, such as sorting timesheets in preparation for fortnightly payments. These developments are very deliberate as Dan is being exposed to the reality of being boss.

He is enjoying the choice and control that comes with the boring work and he understands the complexity of staff needs as well as his own. Dan has matured

and is being assisted to understand that as an employer, he needs to provide a fair work place as well as expect the best support. Dan is clear about the direction of his day and his life and is getting more equipped as he matures. He is confident, he can speak for himself and assert his needs.

Senior staff and I work together to supervise his support arrangements and work with Dan around his goals and preferences. I work with staff to update the resource that explains Dan's needs and if issues arise with staff, we work together to resolve issues in a respectful way. The strategies we use to recruit and train staff means we have minimum unexpected or serious problems.

Collaboration cannot exist where relationships are neglected. Collaboration requires us all to be clear about our roles, feel respected and open to ideas and creativeness. Communication needs to be honest.

While Dan prefers to be the boss of his life, there are times that he needs guidance and support in his decision making. He needs mentoring around relationships, managing staff and at times, needs motivation around the more boring aspects of his life. We have found that if we work in a positive way with staff and assist them to learn about being collaborative, Dan responds well. His life broadens. Everybody is growing and learning in the workplace. Life can be damn fine.



Dan presenting with his friend and former support worker, Michael.

***Collaboration cannot exist where relationships are neglected. Collaboration requires us all to be clear about our roles, feel respected and open to ideas and creativeness. Communication needs to be honest.***





# Being in control of our supports and other tales of irony. Karin Swift

**Karin Swift** has worked in a wide variety of roles in both community and government settings over the years. She is President of Women With Disabilities Australia (WWDA), is on the Management Committee of AMPARO Advocacy and is employed as a Project Officer at Queenslanders with Disability Network (QDN). Karin has worked proactively with her service provider in managing her individualised supports since she moved out of home over 23 years ago. For the past 19 years she has shared a home with her husband David who also lives with a disability and receives formal, individualised supports.

In this article, Karin explores what being in control of her formal supports looks like and how this meshes with both her work and personal life. Drawing on her experiences, Karin outlines some bottom lines that define how she and David engage with their paid support. She also encourages readers to consider their own as we collectively move to having more choice and control in our services and supports

## Being in control of our supports and other tales of irony

I begin writing this article on the tail end of a hairy long weekend. Hairy, not because we partied the weekend away, alas our hard-core party days are over (we are now in our mid-40s and our lives look very different to how they looked in our mid-20s). The reason our weekend had its challenges was because we had a lot of last-minute disruptions to our formal supports. From Friday evening to Monday evening we had changes to six out of seven scheduled support shifts.

One may think it's impossible to maintain control in such an ever-changing, chaotic environment, and I'd be lying if I didn't admit that tears were shed by about the fifth roster change. However, on reflecting on the weekend that was, the fact that we have control (albeit tenuous at times) of our supports is what got us through a particularly difficult few days.

We get our supports from a fairly traditional, large service provider. Sometimes our support is shared, however, it is also designed to be flexible and separate to meet our different needs, goals and changing circumstances. We look forward to continuing to explore more flexible options, such as self-management, as we transition to the NDIS. We've recently been through some changes with our service manager and service facilitator. Our service provider has someone you can call on 24-hours a day if something goes wrong. The service manager (God love her) makes herself available at all hours of the day or night, often fixing things that have gone wrong due to a lack of communication or if they cannot get in touch with us during the day.



*We get our supports from a fairly traditional, large service provider. Sometimes our support is shared, however, it is also designed to be flexible and separate to meet our different needs, goals and changing circumstances. We look forward to continuing to explore more flexible options, such as self-management, as we transition to the NDIS.*

Because we both work it's often not possible for us to contact our service facilitator between the hours of 8.30am and 4.30pm. The "shift fill" arm of the service has its challenges. While well meaning, they are a large team, often working in isolation and do not necessarily know the intricacies of our household, the dynamics of our staff team and how to think outside the box and be flexible in times of crisis.

Yes, life can be messy. Sometimes I feel like I spend more time in conversations with the people providing my supports than I should and that things go wrong more often than they should. Despite the messiness of life and the fact we have a large service provider, we have implemented a number of strategies (or bottom lines) over the years. These ensure that our own standards of service are met and there is some semblance of normality (and sanity) in our everyday lives and the impact of the service on our personal lives is not too great. These standards include:

### **1. Our relationship is our number one priority**

We have been married for 19 years. Regardless of what's going on with our support, we made a promise to ourselves years ago to put ourselves first. This means taking time out to talk if we've had a rough day. It is important that our support workers are able to flow with this and sense when we need time out and to be able to fade into the background if we need privacy. It also means that occasions such as anniversaries, birthdays, date nights and other family celebrations are sacrosanct and support needs to be flexible so we can honour these occasions.

There have been times where we have been forced to make some difficult decisions regarding our support in terms of our relationship. For example, it is important to be able to quickly identify when a worker match isn't right or a worker favours one person over the other. We have learnt over time that it is important that these issues be addressed quickly so that the issue doesn't impact on our relationship.

### **2. Work is our number two priority**

A close second to our relationship is the value of work in our lives. We come from solid-working class

families who ingrained in us the value of contributing to society, working hard and achieving goals. For us, paid work is an essential part of our identity and forms how we give back to society. It has always been important to me that a primary function of my formal support is to assist me to be ready for work each day. This needs to happen fluidly, with little or no disruptions.

There have been times where workers have dropped out suddenly and we have learnt there needs to be back-up plans and back-up plans for the back-up plans. This ensures that any disruption to our service provision has a minimal impact on our employers and even more importantly, a minimal impact on our image as competent, professional workers.

### **3. Our home is our home first and a workplace second**

It is in our own best interests that workers who support us in our home do so in a safe manner where the possibility or risk of injury to either party is minimised. However, all workers coming into our home realise that it is our home first and a workplace second and this acts as a safeguard against institutional practices or imagery invading our home.

I'm no Martha Stewart but neon exit signs, policies, procedures or rosters pinned on the wall or emergency evacuation procedures by the back door do not match our home décor. Things that are required to have a place (such as care plans or transfer documentation) blend into the natural surrounds of our home, such as our home office or a book shelf, and purposely don't look out of place.

We encourage our workers to engage with us around what is needed rather than follow a set list of tasks or a train-track institutionalised routine. Due to the busyness of our lives, we need to be able to come home and relax, feel comfortable and unwind in whichever way we need and it is important to us that our supports can accommodate this. I'm sure this isn't in the rules but each one of our workers knows how to pour us our favourite stiff drink if we've come home after a particularly taxing day.

### **4. We have ABSOLUTE control over who enters the front door. It's our home, not the service provider's**

The ultimate control anybody can have in their own home is to decide who enters it. We have held steadfast to the vision that we get to say who enters our front door. This means that if there is a worker change, our service is required to inform us. This had led to intense discussions with shift fill staff when a worker we haven't expected, arrives at our front door. This also means that shift fill staff can't just take the easy way out and fill a vacant shift with someone we don't know.

We need to okay everyone that comes to our front door. It's our last bastion of control, and a way that we protect what's ours. Our service provider also manages two medium sized residential facilities. Being vigilant about who enters the house is one way of ensuring practices of these facilities do not creep into our home.

*It requires a clear vision of what a good life is for the person or people receiving support and how the support can make their lives better on their own terms.*



## 5. Blurring the boundaries can be okay if that is your choice

We have been fortunate enough to develop some long term relationships with some wonderful people who have come into our lives in a paid capacity, both while they have been with us and in some cases even after they have moved on. Some members of our support team have been around for many years and it's impossible not to relate to them on a personal level as by our very humanness we all have lives and things going on.

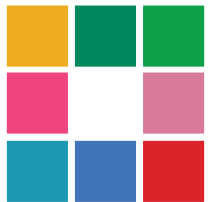
Over the years there has been a mutual sharing of good and bad times in our lives: the sudden loss of my brother seven years ago, the death of my support worker's beloved dog, my mother's health declining in recent years, and a support worker's recent engagement. We have found that maintaining hard and fast rules about professional boundaries doesn't necessarily work for us. This doesn't mean that everyone who works for us becomes our best friend but we have found that sometimes relationships develop naturally and that can be a pretty great gift.

## 6. Keeping our housing separate from our support

While for many people with disability this is not the case, we have found that to maintain control of one's supports the separation of housing and support is critical. This means that these two functions should be provided by different providers so that, in the event of someone's housing being in jeopardy, their personal supports are still in place and if someone is having difficulties with their supports, their housing is still secure. Our support service has nothing to do with our housing and we like it that way. We have a clear tenancy agreement with our landlord. We have control over who we live with and who supports us in our home and these roles and functions do not get confused.

It is important to realise that similar strategies can be implemented in almost any service setting regardless of the service-type. It requires a clear vision of what a good life is for the person or people receiving support and how the support can make their lives better on their own terms. This is something all people with disability have the right to define, or have any support necessary to define for themselves.

Experience has shown me that when these bottom lines have been crossed, David and I have had to make compromises that undermine how we want to live our lives. Similarly, when these bottom lines are understood and respected by those providing us with support, we can enjoy our lives and embrace the chaos of a life well lived.



Bringing the good life to life









## Have you seen our website designed to resource people to bring the good life to life for people with disability.

This website contains a broad selection of articles, videos and ideas drawn from CRU's existing resources and over 20 new short films. It also has lots of interesting content from around Australia and the world. The content is useful for people with disability, their families, friends and the people who support them – both paid and unpaid.

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

visit [www.thegoodlife.cru.org.au](http://www.thegoodlife.cru.org.au)

The website contains 6 pages that cover the following topics:

-  **The Good Life**
-  **Getting Started**
-  **Including Others**
-  **The Role of the NDIS**
-  **Funded Services and Support**
-  **Blocks and Barriers**

Under construction **COMING SOON!**

 **Keeping on Going**

 **The Bigger Picture**



# Valuing expert advice and support.

## Sue Duncan-Kemp

**Sue Duncan-Kemp** is currently involved in the provision of NDIS Early Childhood Early Intervention Services in South West Queensland. Prior to that she worked as a Senior Consultant with NDIS Participant Readiness at CRU for two and a half years. Sue has more than 30 years' experience in the disability sector working in roles within government and in the not-for-profit sector.

She began her working life as a Speech and Language Pathologist and from early beginnings working in large residential settings developed an ongoing interest in what it takes to enable people with a disability to live ordinary (and extraordinary), meaningful lives in the communities of their choice. This interest has influenced her work as a project manager for institutional reform, a service manager, and a practice and policy developer.

## Valuing expert advice and support

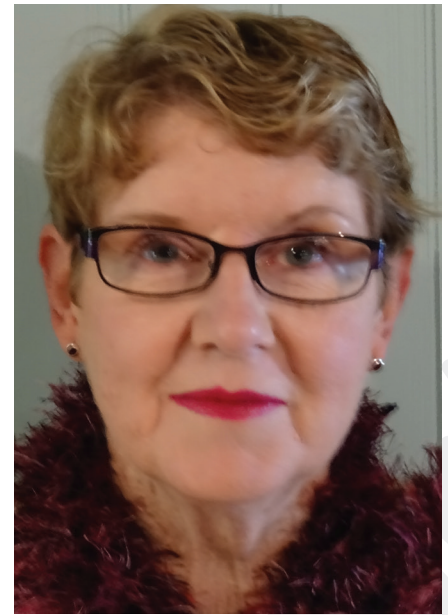
I started my work life as a Speech Therapist and I am a big believer in the value of professional advice and expertise. That said, a few decades of experience has shown me that “expert” advice and support on its own doesn’t automatically result in a good life for people with a disability.

Allied health and other professionals develop their knowledge through years of training, research and practical experience and through their connection with peer networks where they can gather and share wisdom. The advice and supports they provide can improve quality of life and well-being, assist in learning or maintaining skills and modify activities and environments to enable greater participation and independence.

Expert advice is something we all need from time to time - as a netballer of dubious ability, I have greatly appreciated the expertise and healing touch of my local physio. As a speech pathologist, I have provided support and advice in areas such as speech and language development, using alternative communication strategies and devices, eating and swallowing. I have worked with peers from different professional backgrounds to help people identify what is important to them and the activities and strategies that will assist them to maintain health and well-being, achieve goals and overcome hurdles.

The right intervention, from the right people, at the right time can create enormous positive change in people’s lives, but with the range of expertise on offer it would be easy to build a life of therapeutic intervention when what most of us are really after is a life that we can enjoy and some thoughtful assistance from time to time to make it possible.

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It would also be easy to defer unthinkingly to the authority of the “expert” or the “professional” when what is more helpful to recognise that the value of “expert” advice lies in it being provided thoughtfully in the context of who we are as individuals and the role we need it to play in creating or sustaining the life we want to live.

Over the years professional peers, families and people with a disability have been generous in sharing their experiences and knowledge. This has shaped some thinking about the value and role of professional expertise and what good quality support might look like that I hope is useful to share:

- 1. When people are clearer about the life they want to live, they can be clearer about when and where “expert” advice might be helpful**

A work colleague talks about the important things in her life - her job, being able to live in her own home with her partner, going to the football to watch home games and being able to meet friends for dinner at pubs and clubs for a night out.

To do these things she needs assistance from a support worker; equipment to get around, to use a mobile phone and computer at work and to eat and drink; modifications in her kitchen, bathroom, workplace and car. She gets advice from a speech pathologist, occupational therapist and a physiotherapist.

Rather than being “in therapy” for life, she seeks advice when it is needed and she engages the required expertise on her terms, outlining the outcomes she wants to achieve through the support, advice and equipment they provide.

## **2. There are no pre-requisite skills required to be able to live your own life**

I find I can get stuck thinking that there are so many important things that young children need to learn to be ready for the ordinary and everyday things that other children the same age do. My thoughtful colleague gently pointed out that as an adult she can't get out of bed or have a shower and clean her own teeth without support, but she has a university degree or two, works, advocates for others, is a loving mother and owns her own home. She could have spent years trying to master the first list and never got to the second.

Allied health professionals can assist with skill development, early learning, communication, self-care and daily living, gross and fine motor but don't wait till you've got the right “therapy” or achieved a therapy goal to start doing the things that are important, fun and fulfilling in life. Good professional support should enhance the opportunities for a good life, not get in the way of it.

## **3. People know the most about their life and what is needed**

A young athlete who lives a very active life tells me it is really helpful to talk with a physiotherapist and/or an occupational therapist when she needs a new wheelchair, but she always thinks carefully about who she gets advice from and is assertive about what she needs – she is quite clear that her chair needs to be light, manoeuvrable and sexy looking to fit her image and lifestyle.

She engages expert advice to ensure she gets the results that are best for her. By setting goals that are meaningful to her she has greater control over the outcomes.

## **4. The best allied health support doesn't take place in the therapy room and it won't always look like therapy**

The mother of a young man just entering his teens said her son doesn't do well in therapy – he doesn't like to do drills and exercises because he doesn't see the connection to what he really wants to do in life. He finds it difficult to generalise and transfer skills from the therapy room to real life situations. She says what works best is getting good advice and then using it in the real life situations.

As a family of adventurers who like to ride bikes, they have engaged an occupational therapist to break down the task of learning to ride a bike to make it easier for her son. In the early years he rode tandem with Dad and rode scooters to improve his balance (real life activities he loved) and by using a range of everyday activities he learned to ride independently.

## **5. Choose the right people to work with you**

We all learn best from people we like and respect who are knowledgeable in their field.

The older and more experienced I get the more important I think it is to choose the right people, so I asked some of the people I respect most to share some brief thoughts about what to look for when choosing the right person to provide expert advice and support.

## **Professional peers said...**

Someone who:

- understands and appreciates the impact of disability for the person and their family
- has expert knowledge and experience specific to the disability and the issue at hand
- can communicate expert knowledge in a way that is easy to understand and apply to real life situations
- is good at listening and offers ways of doing things that work for the person and their family
- believes in the potential of the person with disability and is on their side
- can talk from a sound evidence base and help the person build their own understanding and knowledge.

They also said to choose quality before quantity and cost.

## **People with lived experience said...**

Someone who:

- knows their stuff and can provide the expertise needed
- listens and is honest, respectful and not patronising
- is creative, thinks outside the box and helps problem solve ways of doing things that work for me
- has a passion for what they do and can go at my pace
- helps build knowledge, understanding and confidence
- can provide expertise and challenge my thinking while still showing respect.

Families and people with a disability also said to trust your gut instinct – you know yourself or our child best and what is needed.

At the heart of good support, no matter who provides it, is a thoughtful and respectful relationship between those of us who offer knowledge, expertise and support and those of us seeking to use others advice, expertise and support to maintain or improve our day to day life.





# Personal assistance. What it is and what it is not - Excerpts. Judith Snow

**Judith Snow, MA**, was a social inventor and an advocate for Inclusion. Her internationally recognized work included consulting and workshops on person centered planning, personal assistance, support circle building, family support and inclusive education. Her goal was to foster an understanding of how people with disabilities can be full participants in communities everywhere, which she did until she passed away in 2015.

This article is a selection of excerpts from her article “Personal Assistance. What is it and what it is not”. It can be viewed in full at Inclusion Press: [inclusion.com](http://inclusion.com).

## Personal assistance. What it is and what it is not.

Personal assistance is a form of support for people who are labelled disabled. People who have been given a disability label are people who have an unusual limitation in their physical functions, their thinking and/or their emotional expression. For example, they may use a wheelchair for mobility, or their speech may be inarticulate or they may have thoughts and perceptions that other people don't have.

In the last fifty years many people with physical, cognitive or emotional support needs, along with family and friends, have fought for the opportunity to live, work, and participate like “regular folk”. They needed a different response than society has been accustomed to providing. They weren't going to become “normal”, they didn't want to settle for stereotypical roles, they didn't need to be “cared for” and they certainly weren't prepared to die. Leaders invented the unique support they required and fought to make it widely available.

They invented personal assistance. What is personal assistance? It is not being a nurse, a butler or a housekeeper although at times it may resemble these roles. Personal assistance is functional support provided through a personal relationship. It is a response that makes it possible for people with unusual abilities to participate fully in the community, contribute to society.... and have great lives.

Personal assistance involves assisting in the daily tasks that a person cannot carry out by themselves or that they find so time consuming as to interfere with other important activities. These tasks fall in the areas of hygiene, nutrition, grooming, mobility, and communication. The need to perform these tasks can arise anywhere, any time - at home, at work, out shopping, visiting friends, etc. Personal assistants are the important “sidekicks” who assist people with these essential activities, making everyday participation a reality.

The types of tasks performed by personal assistants are the same in all situations. The actual functions vary depending on the individual who is being supported. For example, one individual who uses a wheelchair and is an accountant may require help with showering (hygiene), food preparation (nutrition), support to get into a suit and tie (grooming), chauffeuring of their accessible van (mobility), and filing and desk set up at work (communication). A person who has cognitive differences and owns her own baking business may require someone to remind her about showering (hygiene), make a shopping list with her for her home and



business kitchens (nutrition), coach her on clothing selection (grooming), assist with budgeting for bus tickets (mobility), and do invoicing and bookkeeping for her baking business (communication). A third person who has extreme mood swings and is an artist may need physical assistance to bathe when depressed, coaching in food selection, reminders about the need to shop for clothes, support to recognize when not to drive, and assistance with advertising and selling creations.

Personal assistance is paradoxical in nature. Like other forms of support, well executed personal assistance is nearly transparent. Just as I don't want to be conscious of the elevator that is transporting me hundreds of feet in the air, and I soon stop noticing the hum of the refrigerator that is preserving a week's supply of food, a skilled personal assistant can perform his or her functions without overshadowing the contributions and personality of the person who is being assisted. When I am giving a speech to two thousand people, the audience remains unaware of the bathing, grooming, wheelchair maintenance, chauffeuring, and note taking that got me to the podium.

Unlike an elevator or refrigerator, though, the person of the personal assistant is an essential element of the job. Personal assistance is an ongoing transaction between two people. It is a dance which is led by the person who is building and fulfilling their place in the community and who relies on the interface their assistant provides to be able to function in an otherwise inaccessible world.

Each person in the dance must be fully committed to the dance. The personality, interests and skills of the assistant and the supported person must complement each other. Each must bring a willingness to be with each other, open themselves to each other, be honest, straightforward and respectful, and each must responsibly ensure that the leader of the dance really leads. The leader is, of course, the supported individual.

Personally, I hire only energetic people who love to drive, are physically well and strong, and who are motivated to change the world. Why? Because I travel a lot as part of my work, I am active for fourteen to eighteen hours a day, I go into inaccessible places fairly often and I am an activist building an Inclusive world. My personal assistants have to be quick, strong and motivated just to keep up with me. Another person with the same sort of quadriplegia could be much more interested than I am in neighbourhood activities, like gardening, church and going to movies and theatre. Their personal assistants would need to be very different persons.

These essential qualities of personal assistance -- transparency and relationship -- are rarely understood or recognized. A number of standard practices still exist that diminish the potential of this support. First, individuals are rarely provided with the money and the opportunity to hire their own assistants. Instead money flows to agencies and schools which, in turn, hire a cadre of workers and assign them a "case load". Supported individuals have no choice over the identity of their assistants, their job descriptions, or the type and means of their training. Consequently, the personal nature of the working relationship doesn't get established and the support doesn't become transparent. The subsequent activity cannot lead to sustained community participation.

In 1979 I was a chronically ill patient in a state supported hospital for people who are expected to die of their physical problems. In 2001 I am a self employed homeowner who works internationally, employing four individuals. Neither my physical limitations nor my mental acuity have changed much over the years. What did change was that the province of Ontario, Canada was persuaded in 1980 to pay me to hire my own personal assistants. I was put in the driver's seat of my own life.

Another limitation on the acceptance of personal assistance as the ideal support vehicle is that the powerfully personal nature of good support rarely gets recognized and nurtured. A well supported individual and a truly attentive personal assistant typically form a good friendship - one that often lasts long after the job has ended, and may even deepen into love. Agencies often try to ignore or forbid such intimacy, leaving both supported individual and assistant vulnerable to a host of difficulties.

Confusion of roles, emotional fragility, misunderstandings, even abuse are rampant in agency-driven support. Caregivers blame the clients and the service users blame the agency and staff. In reality, the problems arise because the essentially intimate nature of personal assistance is being ignored or suppressed. Rather than guide and encourage two people to take on a uniquely vibrant journey in their lives, agency driven policy usually assumes that nothing is going on and mandates that nothing will happen -- instituting denial. Both people are expected to act like robots, and the capacity of the relationship is diminished, leading to less participation from supported individuals and dissatisfaction among workers.

In reality intimacy is an ordinary aspect of personal assistance. This intimacy is

not sexual. It arises because people are in physical and emotional contact, sharing a deeply personal experience. Their communication has the potential to reach profound, nonverbal levels. Any intimacy has the capacity to spark love and hate. Personal assistants and supported individuals experience this emotional, spiritual roller coaster as an almost daily matter of their lives. This must be recognized as a fact. People on both sides of the relationship must be offered support to recognize the true nature, value and power of their experience.

I have an active support circle of friends and colleagues. I also have four to six personal assistants at any particular time. Several members of my support circle make themselves available to hear assistants' concerns, explanations and proposed solutions. My support circle does the same for me. From time to time, and especially when there is a problem, a circle member will bring us together so we can talk about our realities.

Many of my personal assistants have worked for me for at least three years. Several have remain my friends long after working for me. I believe that this has been made possible because we are sustained by my community in negotiating the intimate aspects of our journey together.

Personal assistance is an essential evolution in human support. It makes it possible for a much wider diversity of people to live, thrive and take their place in the world. As a community support, personal assistance deserves better funding, deeper understanding, greater visibility and wider availability. Governments must adopt personal assistance as the support of first choice, not last. Schools must list personal assistance as a valued career choice. We all must recognize that this support is as essential to fifteen percent of our population as transportation and sewage disposal is to all citizens. Our communities will be stronger when we recognize, celebrate and adequately resource this relationship-based vehicle for creating and sustaining full participation.



# Reinventing Emma - Excerpts.

Emma Gee

**Emma Gee** is a public speaker, author and consultant who lives in Melbourne. Her work draws on her experiences as both an Occupational Therapist and a stroke survivor. Through her reflections on being an allied health professional and a patient she is well placed to discuss the realities and challenges of person-centred support. For more information please visit her website: [emma-gee.com](http://emma-gee.com)

The following is a selection of excerpts from her autobiography "Reinventing Emma". These excerpts commence after Emma is recovering in hospital following surgery for an arteriovenous malformation (AVM). The AVM caused a stroke and there were complications from her surgery.

## Reinventing Emma

As I became more awake and aware of my surroundings I found my life depended on and was dominated by hospital staff. In my former life nurses and other health professionals were just part of the team, but now as a patient my relationship with them was quite different. I was helpless, a child, so reliant on their good grace to get through each day. And, as in all cases, there were wonderful staff members and those who were not so kind. Some, without realising it, made me feel quite humiliated in my new role.

In those first few weeks I was unable to look after my most basic personal needs, like washing my hair...

Although I was feeling so traumatised being in this new body, I felt forced by the hospital environment to keep up. For me each event I faced was enough to deal with in a lifetime, but to others it was just part of the daily hospital checklist of tasks. I didn't have time to recover from one activity before being thrown into the next. The staff seemed to think that if I was given time to contemplate the difficulty of what was happening, I would never move forward. [Page 101]

Some nurses made me feel like a person rather than a patient. Jacqui was my favourite. She would carry out each task cheerfully without complaint. Even when giving me a sponge bath, rather than leave me lying naked on the bed, she would only uncover the necessary parts, ensuring that I remained warm and maintained the tiny bit of dignity I still had. She made me feel special, whether opening my curtains for some sunshine, or reading my get-well cards. She listened to my muffled speech and grunts and patiently attempted to figure out what I was saying, and moisturised my dry feet.

At night Lee and Ruby continued the amazing care that Jacqui had shown. Lee was so gentle in her manner and wore her soft grey hair in a bun on the top of her head, reminding me of a fairy-godmother. In her presence I slept better, knowing I was in good hands.



Actually, most of the night nurses were amazing. Knowing they were awake and watching me was so reassuring. I never would've endured that initial phase of my recovery without the generous care I received. My writings capture very humiliating and demeaning situations that prevailed in my diary and mind. I tell these stories to highlight the enormous impact another's words or actions can have on one's recovery. Being aware of those tiny things, often overlooked, can make all the difference. [page 107].

***As in all cases, there were wonderful staff members and those who were not so kind. Some, without realising it, made me feel quite humiliated in my new role.***



**As her recovery progresses, Emma moves from hospital to a rehabilitation centre. In the following excerpts she is adjusting, not only to this new environment, but also to the reality that she now requires support.**

Although I had improved I was still having trouble keeping up with the rehabilitation centre. It was a fast-moving, efficient place, because they wanted me to be independent, but sometimes their careless action and brisk attitude had the opposite effect.

Whether it be forgetting to shut the bathroom door and revealing my naked body to the world, asking me if I'd like a Malteser when I couldn't eat chocolate or swallow properly, failing to put the bed brakes on, or giving me a 'wedgie' while holding the back of my pants when walking me, there were numerous incidents during my stay that reinforced my feelings of dependency and powerlessness. I'm sure these actions were not intentional, but in my AVM victim mentality I saw them as such. Already feeling vulnerable and defeated, I became fairly cynical about the treatment I was receiving and that cynicism certainly didn't help speed my recovery.

In rehab I needed help with just about everything, but hated asking for it. Some people seemed to make the whole process rather difficult. At times the staff seemed too busy to attend to my needs or would frequently avoid eye contact to save time. [Page 127]

**This excerpt begins as Emma has moved in to her own home, following a short period of living with her parents after leaving the rehabilitation centre.**

The chance to be independent was so exciting, but as I looked around my new, empty home I felt overwhelmed and alone. Everything is trapped in big boxes that I rely on others to empty. I know where I want things put but can't move to put them there. It was the beginning of a dark and growing feeling of dependent independence that I still lug around today. [Page 176]

The elation I had felt when I moved into my new home had proved to be short-lived. My newfound independence was replaced with a feeling of helplessness, reliance and doubt. I never envisaged that well over a year after my stroke, I'd still be so heavily dependent on those around me. [Page 180]

**In the chapter "Dependent Independence" Emma describes the challenges of re-establishing her life in the community, in particular finding a balance between accepting the support she needs, and maintaining the independence that is central to her identity and sense of self.**

To be eligible for any service from community organisations, though, I had to highlight in each assessment what I could no longer do - something I preferred not to think about too much. After a number of depressing assessments I was allocated a regular carer from the council for a couple of hours a week.

*I saw that by asking for and accepting support,  
I could achieve a lot more in my day.*

The decision to let a random stranger invade my personal space was not easy. I confess that at first I was defensive, and critical of everything they did. Sometimes they'd begin tasks assuming what needed to be done. "Let's let some light in here and brighten this place up. It will cheer ya up," they might say, pulling up the shutters that I had deliberately left down to lessen the glare that hurt my now ultra-sensitive eyes. Some helped themselves to a choccy or two from an open box, flipped through a book on my bedside table or told me to do things in a different way. While I felt happy to offer them a chocolate or adopt their suggestions, the forceful way they seemed to take over my own home made me feel bitter and resentful. Watching someone else do things that I once could do for myself just rubbed in the reality of my own helplessness.

It was even tougher when they did things their way, without considering the outcome. One carer made my bed, tucking the white sheets in firmly under the mattress. She failed to realise that I didn't have the strength or the control to untuck the sheets. That night when I tried to 'post' my body between the tight sheets, I kned myself in the face, resulting in a blood nose.

Now I'm able to admit that the presence of home carers in my life has been invaluable and I am so grateful for their assistance. But initially it was a frustrating time for me. [Page 176]

I was adamant about still having some control over my new home. I refused to listen to therapists' recommendations that I purchase an electric scooter to replace the rusty manual silver car that I no longer could drive, or modify my bathroom and install rails around my new home. In my state of denial I continued to stubbornly believe that

putting in ugly disabled equipment was a waste of money and unnecessary when I was on my way to a 100 per cent recovery. Accepting any modifications to my home symbolised permanency and disability confinement, and suppressed any chance of hope. Those around me would assume I was no longer improving. I don't think my therapists understood my state of mind and often took my refusals personally. Of course their suggestions were right and in fact did seed the ideas.

In 2011, six years after my stroke, my parents (and main caregivers) decided to move to the country... When they sold the family home, 10 minutes away from my unit, they also took a big chunk of my support with them. I realised how many little things they'd done for me. With my parents leaving, I had to delegate my support. I hated burdening others, particularly my siblings. For several months after my parents left, I tried to live pretending I didn't need anyone to help me. I stubbornly refused to accept or even ask for help, and didn't want to become reliant on strangers and feel the need to repay them for their support.

Jobs like putting out the rubbish and cleaning up dog poo I had gradually let my parents do without feeling too guilty. Now when friends came around to see me I had to ask them to do these tasks, eating into our catch-up time. It seemed to unbalance the relationship, them becoming more like carers in my eyes...

After accidentally locking my keys inside my unit three times in a row and flooding my laundry twice, I realised I couldn't rely on my parents' frequent but irregular visits to help me. I had to structure formal supports into my life. I told myself to snap out of it and began to notice the positives. Gratefulness and resentment can't co-exist...

I gave spare keys to friends, had a friend mind my dog Gilbert when I travelled, began shopping online, caught more cabs and increased my weekly council homecare hours. My siblings and close friends happily took on many of the tasks that my parents had previously done. All these changes empowered me to live independently and I'm sure my parents didn't feel as guilty. I saw that by asking for and accepting support, I could achieve a lot more in my day. I became reliant on my parents more for emotional support, through reassuring phone calls or chats over Melbourne coffees when they came to town.

**In the chapter: 'Life Now' Emma shares the joy in her life and some of the plans she is making for her future, including getting back in to her passion of travel.**

***Accepting their help is better than becoming frustrated  
or interpreting their kind offers as devaluing.  
I'm probably now a better travel partner.***

***As time goes on, the prospect of travelling and holidaying  
overseas with others has become less daunting. So many  
adventures, opportunities and possibilities are ahead of me.***

When travelling with friends I need to organise trips with smaller groups of people. As time has gone on they have become so mindful of my extra needs. Hiring cars, carrying my luggage, making my bed, booking accessible Accommodation or cooking my meals are just some of the things my friends now do that make holidays so much easier. Accepting their help is better than becoming frustrated or interpreting their kind offers as devaluing. I'm probably now a better travel partner.

As time goes on, the prospect of travelling and holidaying overseas with others has become less daunting. So many adventures, opportunities and possibilities are ahead of me.  
[Page 236]

**Reinventing Emma  
by Emma Gee**

**(Openbook Creative, 2016)**

**is available from the CRU bookstore  
or from Emma's website:  
[www.emma-gee.com/-the-book](http://www.emma-gee.com/-the-book)**

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