CRUCIAL TIMES

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Editorial: The Importance of Planning

This edition of CRUcial Times will explore the importance of planning for and with people with disability, addressing the question of why it may be helpful for a person with a disability to make a plan and also sharing some experiences of how that can happen.

In this edition, as we refer to planning, we are particularly focusing on people with disabilities planning holistically for their lives – we are not focusing here on service plans or education plans or the wide variety of care or support plans that form the basis of agreements about the formal support that services will provide.

We are talking about a person and probably their invited friends and supporters, taking the time to quite intentionally name their desired future and then start to take steps to achieve that. This is likely to be a broad vision and plan encompassing the many aspects of life, not just the paid service provision. The question of how a service plan can fit in to a person's broader life plan is an important one, but it is crucial to highlight that these are different types of planning and they have different purposes and priorities. Our writers illustrate that this broader planning is not dependent on funding or formal service, but that when people have done this planning for themselves, then they are much better equipped to make good use of any funded supports that are available.

Debbie Naughton describes how the service she works for engages some of the formal stakeholders so that people have a better chance of achieving their goals. For people who have been disconnected from their families – who don't have that steady person who will carry a vision for them or with them then it is important that we think about who will listen to their vision for themselves and who will resource people to carry it out now and also carry it on. The role of the service in planning is critical. Debbie describes how their service conducts planning that keeps the person in control and then works with them to achieve their goals.

Naming that desired future can empower people to take control of their lives rather than being passive bystanders in existing service systems. Having what you want and don't want clearly articulated is also very helpful in engaging others to work with you on achieving the life you want. We appreciate that the reality for many people with disability is that they require assistance to do what they want to do with their life and that this assistance is likely to be provided by a number of people. Ensuring that all these people are working in the same direction and that that direction is what the person actually wants is not easy and thus some formalising of the direction and the agreed steps to get there can be helpful. This is slightly different to the general population who can usually afford to have a vague life plan in their heads and modify it as they go. They are not as dependent on others to bring the plan to life and the consequences of not having a plan are also not usually so great. When people with disability, and the people closest to them are not setting the agenda, then others who don't know the person will set the vision of what's possible and it will be based solely on their disability needs rather than who they really are.

> ***Our plans need to start with a vision of what we want and if that vision is too small or apologetic or limited then we run the risk of compromising the person's future***

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Editorial Margaret Rodgers, Director

While some deliberate and formal processes might be helpful to get started, our writers describe how this can ease back over time to become more a way of thinking with regular top-ups and reviews rather than remaining highly formalised forever. As Debbie Naughton says, it is still there but it is in the background not the foreground. Julie Van Oosten also shares her experience of witnessing good things happening that weren't written in the formal plan but that wouldn't have happened without the planning. The fresh thinking stimulated by a creative planning process opens us all to see new possibilities.

When I was travelling in Canada last year, I was walking over a very steep bridge and towards the top there was a warning sign, saying "Limited Vision". While the risks are a bit different, I thought that we could do with similar warning signs when we are thinking about the lives and futures of the people with disability that we know and care about because our plans need to start with a vision of what we want and if that vision is too small or apologetic or limited then we run the risk of compromising the person's future. I find that having a group of people working on naming and writing the vision can help us all to be braver.

The word vision can be confusing. It can sound very grand or somehow mystical. However, just like on that bridge in Canada, it's about looking forward as much as we possibly can to see what's over the horizon and, to the extent that any of us can control what happens in life, being as ready as we can be for that.

Clarifying and articulating what is most valued and desired for now and into the future is a way to take some control over what will happen. Most people with disabilities or their parents that I meet already have a vision. For many, it was there before the disability but it may have been dinted and diminished over time. Often it has not been written down or said out loud but people do usually know what they want if they can take the time to sit and reflect on that and reflect on what is valued for everyone else in their family and community. Writing this down or finding a way to share with others can help with carrying it out now or carrying it on in the future.

Josey McMahon and Kate Alcorn discuss sharing this with family and friends. They both talk about writing down two vision statements; one for the person, either written by themselves or by people who know them best, and then a vision statement to guide their family, friends and supporters in how to assist them.

The plan follows the vision because when we know what we want we can work out the steps to start making it happen. As the goals on that plan are achieved or partly achieved or as they are tried and found wanting then the plan will be modified and new plans made. This is what most of us do in life; the difference being that we may not always be so conscious or formal about it. In her article, Kate Alcorn, shares with us her journey over the past few years of setting a vision with family and friends, making plans and achieving them so she can now say with some authority 'My life has gotten real good' and her mother Carolyn can say that while there are challenges from time to time, this is worth it. Their vision of Kate living in her own place and forming an independent life in her community to the degree that she is able is definitely well under way.

Our writers offer many very practical suggestions on how to get started with planning. They recommend being quite intentional about planning and setting time aside; inviting others to be involved on a regular basis and engaging someone to facilitate or assist with the conversation. There are a variety of planning tools available but whatever you use the basic premise is to start with a big vision, full of possibilities and then break it into small achievable steps. Julie Van Oosten cautions about only seeing the person through the lens of disability and missing the whole rich picture of who the person is. Obviously the particular needs that result from a person's disability need to be taken into account but we are suggesting that they are not addressed as the first or only needs that the person has.

The beauty of this process is that every plan is made to measure to suit the unique talents and skills, needs and desires of the person at the centre of the planning. Planning however is not an end in itself. It is a means to a good life for the people we know and care about and it can be a safeguard to ensuring that that good life can go on in the future.

Margaret Rodgers

Chief Executive Officer

From the President Sharon Daley

From the President

My name is Sharon Daley and let me start by saying that I am very proud to be a part of CRU. I have been on the Management Committee of CRU for the last two years and in December of last year I was elected president. Volunteering on the CRU committee is one of my favourite things that I do with my time. Being a part of CRU is really special to me and I believe it adds value to my life. So it is my hope to be able to give something back for this great experience during my time as president.

I have always had an interest in people with a disability, and their families, as my brother David is labelled as having an intellectual disability…but to me he is just Dave. Dave has his own unit at Kedron and for the most part manages himself independently. Perhaps if he was here he would say that we don't allow him to be as independent as he would like…but hey, once a big sister, always a big sister.

To be president at this time is a rather overwhelming notion since the NDIS is set to be up and running by the middle of next year which means we are all navigating through some unchartered territory. Undoubtedly, the biggest piece of work CRU will do during the next 18 months is to help people plan and prepare for the NDIS in Queensland. This is a large and exciting project for us which will complement the ongoing work of CRU, which will be continuing as normal throughout 2015. All CRU events are listed in the Upcoming Events section of the CRU website.

For me, this year, I plan to work closely with the stewardship group to ensure that the fundamental values of CRU are continually upheld and that we live our mission to engage a broad range of people in a movement for change so that people with disability will be welcomed and appreciated as they take their place in their communities. I will work closely with the other members of the management committee to ensure we have organised meetings with meaningful discussions that allow the great work of CRU to continue.

Sharon Daley
President

During the compilation of this edition we held an AGM and changed presidents so we decided to ask the outgoing president Matt Stone and also the incoming president, Sharon Daley to make a contribution. Sharon has been on the Management Committee since 2013 and we welcome her to the role of president. We are very pleased that Matt will continue to serve on the CRU committee.

CRU Committee Members 2014-2015

Sharon Daley	President
Matthew Stone	Vice President /Secretary
Sherryn West	Treasurer
Josey McMahon	Member

CRU Staff

Chief Executive Officer
Margaret Rodgers

Senior Consultants
Lisa Bridle
Susan Duncan-Kemp

Finance Officer
Bill Kyle

Consultants
Suellen Welch
Catherine Laherty
Trina Steed

Information Consultant
Hugh Rose-Miller

Administration Officers
Kim Jensen
Bobby Noone
Dione Henry

Administration Support
Kathleen Fleming

From the outgoing President Matt Stone

From the outgoing President

Thank you to everyone who supported our recent AGM. I have thoroughly enjoyed serving as CRU's President for the past three years. I'm grateful for the opportunity to sign-off as President in CRUcial Times by sharing two examples of planning for success and planning for positive change.

The first example is one of collaboration and the value of listening to others when making the big decisions. Every three years the Management Committee and staff work together to develop a Strategic Plan and for our current Strategic Plan we also involved input from the inaugural Stewardship Group. Envisioned as part of the previous Strategic Plan, the Stewardship Group was established for a one-year trial in 2013 with the purpose of bringing together a wider and larger group of leaders from throughout the sector. We asked for their ideas on the following areas: Safeguarding the Vision and thinking of CRU; Contributing to the analysis of sector developments & issues – local, state and federal; and Providing strategic advice and thereby assist CRU to stay relevant and 'in front of the game'.

The Stewardship Group is a good example of the type of planning that is undertaken within CRU. With a small management committee that meets monthly for about 2 hours, it was obvious we did not have the time needed to discuss, analyse and reflect on many of the bigger issues affecting our sector. The majority of our time was focused on issues of governance, financial management and compliance. While time and energy is always devoted to these to ensure CRU remains a viable and sustainable organisation, the establishment of the Stewardship Group was a tangible attempt to achieve the deeper conversation and analysis we were seeking. The plan to establish the group included some key steps such as an Expression of Interest process to identify potential members and a Terms of Reference to guide the group in its discussions. An evaluation process was also part of our planning to review the group in one year. The review process has led to the re-establishment of the Stewardship Group for a two-year period commencing January 2015.

The second example comes from the 2011 International Initiative on Disability Leadership (IIDL) conference . If I feel I am distracted or unfocused, this lesson helps me refocus on the 'why' of my work. One of the key speakers was the then Washington State Director of Developmental Disabilities, Linda Rolfe. Linda was also a contributor to the CRUcial Times edition on Practical Leadership in September 2010. Linda has been a leader of significant change in the area of employment for people with severe disabilities in her state and in both her article and conference presentation, Linda was very clear about the importance of work for everyone. Listening to Linda at the conference, I wrote down one of the key learnings she shared with us about how her department actually planned for and set about dramatically increasing the participation rates of people with severe disabilities in paid work. Linda said:

"The main thing is to keep the main thing the main thing"

There have been many times when I've been really busy with 'stuff' and I've had to stop and ask myself, "What has this got to do with people with a disability having a good life?" Is this task or deadline really what's important? Am I keeping the main thing, the main thing? Too many times I would say busyness and pressure at work have taken my focus off the main thing. I've since printed and laminated Linda's message and stuck it up in my home office as a constant reminder to not lose focus on what's important and what really needs doing!

Cheers,

Matt Stone
Former President

> *"The main thing is to keep the main thing the main thing"*

From Vision to Action Through Planning

Julie van Oosten

Julie van Oosten has been involved in planning for over eight years in a number of roles. She is currently the team leader at Pave the Way, Mamre Association Inc, in Brisbane, Queensland. Pave the Way engage people with disability, their families and friends in planning for the future. They are not involved in service provision, but instead assist with planning, support circle establishment and currently with preparing Queenslanders for the roll out in 2016 of the National Disability Insurance Scheme.

In this article Julie reflects why people plan, the benefits of engaging an experienced facilitator and the value of including others in the planning process. Julie highlights the value of remaining grounded in the ordinary and how this thinking is fertile ground for clarity, enrichment and new possibilities.

From Vision to Action Through Planning.

For people with disabilities, their families and networks, a facilitated planning session can be a very positive experience for all involved. It raises expectations about what is possible for the person to lead a good life and as a result passes on hope, knowledge and authority to the people who it rightfully belongs to - the person at the centre of the planning, their family and those who love and care about them.

In the disability sector the kind of planning we often hear about is planning for service support or funding purposes. Whilst this has its place, at the organization I work for we engage in planning that is family driven and which we refer to as *from vision to action through planning*. In other words, it is planning that, at its heart, is about articulating a vision for a good and safe life for the person both now and into the future. This kind of planning places the person at the center and explores their personal hopes and goals in life. We focus on what is typical for the person's age and gender, but also what is unique about them; their gifts, passions, hopes and interests in life. This is the lens that informs the vision and frames the planning that follows.

Planning can also be a way of thinking that informs every day decisions and actions. To get to this point however, one must know where one wants to go and planning can be an effective tool to begin this journey.

> ***The facilitator can pose questions and frame them to reorientate people's understanding of how disability is understood by them and in the world***

In my work, planning usually involves engaging people in a formal process. For example, a small number of people are invited by the person with disability and/or their family to come together for a few hours. They enjoy some hospitality and together contribute their ideas, perspective, information, or even just a good dose of optimism or creativity.

For many families though, there is a reluctance to engage in a formal planning process. This can sometimes be due to the day-to-day demands of raising a family and/or working that planning can seem like just another task to add to the long list of things to do. However, engaging in a planning session can actually be quite an effective and powerful process for a number of reasons.

Perhaps most importantly, it means setting aside time in the busy-ness of life and dedicating a few hours to stop. To really stop. To stop shuffling the fear of the future to the deep recess of your mind; to stop thinking that you and only you have to come up with all of the answers, or to stop thinking that funding and services alone will provide you with the answers you seek. Good planning is first and foremost about setting time aside and creating a space in order to ask good questions and involve others in the process. Having a facilitator who can pose good questions that elicit useful answers can be invaluable.

When someone facilitates the planning they can be responsible for the process, including managing time and the group dynamics whilst keeping the group moving in a forward manner. A facilitator can bring impartiality, as they usually do not have the same emotional investment as the family and others who are personally involved.

For others, their reluctance to engage in formal planning stems from thinking that it is a big ask to invite others into planning with them, but in my experience this is not usually the case. Not only do they feel valued and honored by the invitation but they actually enjoy being involved in such a process. For some families, there is not a big network to draw from so inviting people in a one-off kind of way has been a useful approach. Asking someone to come and share their experience or knowledge of something you are considering does not constitute a big ask, just a few hours of their time.

If it is not the right time or place for formal planning then planning can take place on the level of a casual and slightly structured conversation with a friend or other family member about decisions that need to be made. In other words, an ‘intentional cup of tea’.

When considering engaging in a formal planning process, it helps to think about the purpose of the planning: what do you want to achieve; what are your hopes and expectations and what don’t you want to happen? Once you have thought about the purpose, it is easier to think about who to invite. For example, if your family member is about to leave school and you want to look at what their life will look like after school, it makes sense to invite some younger people who will have more idea of how to operate in a young adult world. A cousin or neighbour who may or may not be directly involved in the life of your family member may bring typical and ordinary ideas as well as a fresh set of eyes.

Inviting others is also an opportunity to create awareness and understanding among people in your extended family and networks. We often receive feedback about how the process resulted in getting everyone on the same page. This is difficult to cultivate without some level of intentionality and you would need lots of intentional cups of tea to try and achieve the same result.

Inviting others into planning usually adds a richness and energy that is difficult for families to achieve on their own, but involving others may at times present some challenges. Some of the challenges arise when people do not look beyond the person’s disability to who the person actually is and subsequently may not have imagined a typical and ordinary life for them. Unfortunately a person’s disability is often used as the dominant lens through which they are viewed. These are the views they have inherited from a society where the common practice is still to view people with disability as ‘*other*’ and send them away from their communities, their families, and their ordinary life in order to get support. Therefore it is important when planning not to focus solely on the person’s disability or the challenges they experience

In the planning context I see the role of the facilitator therefore, is not to just manage a process but also to model ideas or a way of thinking that will subvert this disability or ‘other’ lens to enrich the planning process. The facilitator can pose questions and frame them to reorientate people’s understanding of how disability is understood by them and in the world. I’m not suggesting the facilitator impose an agenda of their own; this is about giving a perspective that people are too seldom exposed to. The vision, if typical and ordinary, gives weight to this authority and this then can frame all of the questions and answers from there on in.

There are numerous planning tools and processes, with varying degrees of complexity, that have been developed around the world. At my work we use a simple process, which is sometimes modified in consultation with the person and their family. As mentioned earlier we refer to planning as: *from vision to action through planning.*

Once you know where you want to go, you can choose whether or not to embrace the many unexpected opportunities that will present themselves along the way

We start the session with the question '*what makes a good life for someone of the person's age, gender and culture, in this particular community*'. We then spend time on thinking about who the person is, their unique interests, gifts, passions and challenges in life. Time is spent articulating a vision for a desired future based on this information. From here goals are set based on the vision. Finally, each goal is unpacked, to work out what actions are required, by whom and by when. A planning session of this kind usually takes about 3-4 hours and often families review the plan a year or so down the track.

After many years of planning with families, I know that no two planning sessions are ever the same, as they reflect the unique hopes and expectations of the person and their family and the ideas contributed by the group. One of my mottos is 'no-one knows as much as all of us'. Involving others can be full of surprises for everyone involved.

Recently I facilitated a planning session with a family and their 11 year old son who I will call John. This particular session reminded me of the importance of involving one's networks, at a time and place that is convenient to them (usually a Sunday and in the family's home we have found), to imagine the best possible life for the person. It also reinforced to me the importance of the facilitator setting the scene to ensure the group can imagine typically, creatively and better. In preparing the group for planning I anticipated that some people may be looking at John through the lens of his disability, so I began the planning session with a simple question:

'*What does a good life look like for a typical 11 year old boy in your community*'?

The group didn't hesitate to answer: playing Xbox, sleepovers, sports, paper runs, visiting relatives, going down town, or up to the water tower, were a few of their responses. I would wager, that if I had asked this question but replaced 'typical' with 'disabled' they would have imagined the usual segregated services offered to people with disability. By asking a question about a typical life you could see the fear of not knowing shift to the confidence and delight of indeed knowing. This group knew a lot of boys John's age and knew how they spent their time and they eagerly embraced this different way of thinking about John. When planning for what is typical and ordinary, one's informal networks can be more easily welcomed to participate in a meaningful way.

I then asked the group to bear in mind this typical vision for a good life in the process of planning for John. John could do all of those things if he wished - the only difference is he would require support to do some of them. Some of that support can be from support workers and some can come from family and friends.

This particular planning session crystallised for me how proposing an alternative view about disability can assist a shift in thinking. The process we undertook changed the way these family friends saw John and the life they could imagine for him. It seemed to me to be a truly uplifting experience for all of those involved - to imagine this real life, not some segregated second-class version of a life. The magic was not so much in the ideas themselves, but the opportunity it provided for the family's networks to understand John, the young boy, outside of his disability. After all, too often the lens of disability can make life more complex than it needs to be. In addition to changing the group's perception of John, it also gave them an opportunity to play a part in his life. John has paid support workers to assist him and his family, but this was not about support, it is about a typical life for John loved and surrounded by his friends, family and community.

John's family was overwhelmed by the simple process and the ordinary lens we used, as their planning experience up until then had only been with services, resulting in plans based primarily on his support needs. Services can play an important role in the lives of people with disabilities, but as they are usually orientated to working out support arrangements to be provided by the service itself and usually with very few resources, the planning can be rather limited. The plan the group fashioned using this ordinary lens better prepared them to see where the service fits with their plan, not the other way around.

It is helpful to bear in mind that planning, while extremely helpful, is also just a tool. It is a tool to help you clarify where you want to go, what you need to get there and to give you confidence about the decisions you make along the way. Your vision is the most important component of your plan and it will be the compass to keep you on track. If I have learnt anything during the course of this work, it is that many of the good things that happen in life are not necessarily set out in a plan itself, but arise from the journey the person is on in pursuit of their vision. Once you know where you want to go, you can choose whether or not to embrace the many unexpected opportunities that will present themselves along the way.

Steppin' Out – A Journey to Independence

Kate and Carolyn Alcorn and Glenys Bull

Two years ago **Kate Alcorn** moved from the family home to a home of her own – just a few minutes' walk from her work and in the community she grew up in. To help with this, Kate and her mother Carolyn started 'Kate's Crew' - a group of family and friends who meet regularly to help Kate plan for her future, organise her life and live the life she wants to live.

In this article, together with founding circle member Glenys Bull, Kate and Carolyn reflect on what it has taken to bring a group of people together to help start realising Kate's vision and how this can be safeguarded in to the future.

Steppin' Out – A Journey to Independence

"Oh no!" Kate exclaims, when asked if she would like to move back in with her mum. "I used to live with my mum all my life. My relationship with mum is different now - I think I've grown up".

For the past two years she has lived in a town house in the community where she went to school and has worked for the last fifteen years. She shares her unit with people she finds with her mother Carolyn, and together they enjoy the ups and downs of share house living. Carolyn was clear about where she wanted Kate to live. "Our family vision is for Kate to live in her own place and form an independent life in her community to the degree that she is able. As with any young person moving to independent living, there is much to learn and adjustments and allowances that have to be made. It is an ongoing journey for us all, and Kate has continued to surprise us with how well she has done".

This has certainly presented challenges for both Carolyn and Kate. As Kate says, "My housemates sometime never clean. Some people never learn how to use a dishwasher. It's not fair on me. They have to do their share". Fortunately Kate has her support circle, 'Kate's Crew' to assist at these times. However it was not always like this and this goes to the heart of why Kate's Crew was started.

As Carolyn explained "It all came to a head when Kate asked me one day, "What's going to happen to me when you die?" Having lost her father in 1996, she understood fully about life and death and had come to the point of realizing that I may not always be there for her. Up until that point I hadn't thought seriously about this possibility or its consequences for Kate. I suppose I had assumed that family would look after her and more particularly, the family we had asked to be our children's guardians when they were younger.

As my thoughts became more focussed, I realized that should something happen to me, this would not only mean a move to Melbourne where they now live, but also the loss of her job. She would be far from her colleagues at work and her church family and friends. What a huge loss on top of losing her mother!
It became very clear to me that this was not the life that I wanted or dreamed of for Kate."

> ***The members of Kate's Crew are committed to Kate and understanding her needs and dreams.***
>
> ***They also provide the encouragement I need and the valuable perspective of those who are that little bit removed***

After attending a workshop with a local planning agency, Carolyn and Emily (Kate's older sister) were introduced to the idea of support circles. Following this workshop, Carolyn, Kate and some close friends and family subsequently went to another planning workshop which took these ideas further. As Carolyn reflects, "we were challenged to think creatively and plan without a lot of reliance on government help. We were asked to visualise the ideal life we would wish Kate to have and then start thinking how we could make it happen. Our perspective was broadened as we were presented with new ideas, strategies and possibilities. Kate was also taken through a process to help her develop and clarify her own vision for the future. What is amazing is that both visions were very similar:

Our Family Vision for Kate:

That Kate live a safe, full and fulfilling life as a valued member of her community.

Kate's Vision:

To be around a group of people that I live with in my own apartment
- Managing my life,
- Being responsible and independent
- With time to myself.

"Although the idea of starting a support circle for Kate was very daunting for me, in reality it happened quite quickly. A lot of people say they have difficulty getting people to become a part of their circle but we never had that trouble. Kate was so excited about the idea that she was inviting people before I had a chance to catch my breath … and they all said yes." Kate explains "People I've known for years have to be in the circle". "Yes", agrees Carolyn. "It's a mix of family and friends".

This circle of support meets every two months and has been running now for over five years and they gather on a Sunday afternoon at Carolyn's house. "We have the meeting first and Kate shares what's happened in her world since the last meeting and then brings up anything she wants to discuss". "I just say it" says Kate, "what I want to do with my life" and together with Kate, *Kate's Crew* work out how they can help make this happen. The meetings finish with two of Kate's favourite things – food and time with friends.

"It's been a stable group of about 10 of us" says Glenys, a friend of Carolyn's and a founding member of *Kate's Crew*. "Over the last five years we've come to know each other quite well and are all committed to Kate. We're on the same page - with common values and standards.''

Despite the circle forming quite quickly, it has not been without its challenges, as Carolyn reveals. "When *Kate's Crew* first started, Kate felt like everyone was organising her life and she sometimes found it quite overwhelming. As time has gone on, she's come to understand that no matter what is said during the discussion, she has the final say with big decisions. Kate needs time to process what has been said and wasn't always ready to make a response. Whereas now, she's much quicker to say, ''No I don't want to do that", or "I like that". As Kate describes, "my first time planning my future was so hard for me. I have Down Syndrome and my speech is not wonderful. People always have opinions and I felt like I had to do what I was told to do. '' As Glenys was quick to point out, this is less of an issue these days. "She's quite forthcoming about what she wants. She is quietly determined". Kate agrees. "I don't want them to make decisions for me, I want to make my own decisions".

All the members of *Kate's Crew* bring a mix of skills, interests and opportunities. "We go around the circle and talk about each member's gifts. For example, Martin is very practical, so he puts ads in the paper, fixes things at Kate's unit and things like that. We rely on Peter for his computer skills. My brother and sister in law live at the Sunshine Coast [and living so far away] there's lots of things they can't do, but we value their input and Chris (Peter's wife) shares in facilitating the meetings. This facilitation role is an important one. They are responsible for keeping the conversation going and making sure Kate's vision is at the centre of all decision making. Others help out with taking minutes, interviewing prospective housemates and being part of sub committees to solve in-depth problems.

> ***Things don't work out for anybody all the time.***
> ***You've really got to have a vision and want it and hang on to it and***
> ***be prepared for the hard work that will go with it***

As Carolyn explains, “For the first couple of years I had both visions printed out on the table to keep us focussed. Because we’ve been meeting for so long now I don’t feel it’s quite as necessary.”

Glenys went on to elaborate. “Most of the early goals and desires that Kate had, and that we talked about, was to be part of THIS community, - the community she can access. There are plenty of things on all over Brisbane, but engaging in her own local community provides a safety net where she is known and people look out for Kate. It’s not just a matter of activities to fill in time, it’s a matter of getting to know people and being part of a relational community”. And it doesn’t end there. “Whilst ‘the big goal’ of living independently has been reached, it is still ongoing and there is always lots of the nitty gritty to work out. Maintaining and growing in independence does take a long time. It takes a long time for any young person to develop responsible independence. So for Kate, it is an ongoing thing. Most of what we’ve focused on this year is the nitty-gritty”.

A typical example of keeping things going is finding suitable housemates. There are particular things required of a housemate for Kate’s safety (amongst other things) and every time someone moves out, it’s on again. “Carolyn had an idea of inviting some new people in, as a one off” said Glenys. “It’s a good idea to get new blood and fresh ideas. Having a circle that is so close, sometimes we can become stale and need to see things from a fresh perspective.” As well as providing some fresh ideas, it will also give *Kate’s Crew* a chance to hear from people Kate’s age about how they find their own housemates.

Whilst there are challenges from time to time, Carolyn is adamant that it is worth it. “It is hard work, but by the same token you don’t want to hand decisions over to just anybody. I want the people in Kate’s life to know her well enough to be able to help her achieve her goals. Because of my work commitments, Glenys and Carmel have quite often interviewed housemates and this is a great help.”

“I think there’s a tendency to think that once you start a circle, it’s going to be all rosy, but it is hard work.” Glenys points out, “Things don’t work out for *anybody* all the time. You’ve really got to have that vision and want it and hang on to it and be prepared for the hard work that will go with that.”

There are plenty of things on all over Brisbane, but engaging in her own local community provides a safety net where she is known and people look out for Kate.

It’s not just a matter of activities to fill in time, it’s a matter of getting to know people and being part of a relational community

It is still early days but Kate is enjoying the independence of living in her own home. Her unit is within walking distance from her work, which is just as well as she starts work at 6.00am. For almost fifteen years Kate has worked at the local Coles supermarket and is a valued employee. When asked what her favourite thing is about living in her own home, Kate replies, “Relaxing. I got my new lounge suite now” - a lounge suite she paid for with money she earned through extra paid work she did on top of her work at Coles.

With her independence has come confidence and with this, further independence. “Sometimes I prepare my own meal, bring stuff and post it, get to bed on time and go to work on time”. When asked about how her life has changed since *Kate’s Crew* started the answer was clear, “My life has gotten real good!”

Carolyn reflects, “It would be a different situation if my husband was still living. I’m sure we would have eventually considered starting a support group, but as a sole parent I need people to bounce ideas from. *Kate’s Crew* fulfils that for me. I have found that unless you have walked the road, most people don’t really understand the day to day pressures, challenges and decisions that need to be made. The members of *Kate’s Crew* are committed to Kate and understanding her needs and dreams. They also provide the encouragement I need and the valuable perspective of those who are that little bit removed. I will do anything to achieve a good life for Kate”.

“I think Kate is determined to have a good life” Glenys agrees. “She definitely has her own voice.”

“Oh yeah!“ says Kate. “I gotta get all the housework sorted out first”.

Planning To Achieve Insurmountable Goals

Josey McMahon

Josey McMahon is a mother of four adult children, step mother to two adult children, social worker and a passionate advocate for the rights of people with disability to have good lives that have meaning and purpose. She is also the twin of Cathy McMahon. From June 1967 to May 2014 Cathy resided in a large institution, isolated from family, friends and community. Through the tenacious efforts of her sister, Cathy is now living in a home of her own with paid and unpaid support around the corner for Josey and is putting her roots down in her local community.

In this article, Josey outlines the relationship between developing a vision and actioning the vision through strong intentional planning to achieve a good life for Cathy. She outlines the importance of holding the vision tight despite the challenges.

Planning To Achieve Insurmountable Goals.

Cathy and I are twins and were born in the mid 1950's in a small country hospital in South West Queensland. We arrived fourteen weeks premature and were not expected to live. However, due to both of us having great tenacity we survived the odds. It would appear that we acquired our disabilities at birth, possibly either too little or too much oxygen and very premature for that period of time.

We grew up in a large family with four brothers and three other sisters. Cathy remained living at home until the age of twelve years when it was decided she would be best cared for in an institution over an hour's drive from our family home in regional Queensland. Shamefully, she remained living there for the following 47 years. In May 2014 Cathy finally moved from the long stay institution to a home around the corner from where my husband and I live. We hope this is the start of a new chapter.

Less than seven years ago, moving Cathy into community from a long stay institution was no more than a dream in my mind. I wondered whether it would really be possible for Cathy to live in the community in a place that she could call 'home' and participate in 'ordinary' community life and be a 'valued, contributing member' of her local community. After all many people, including some professionals and family members, kept advising me that she was being well looked after and that she would never adjust to community living after being institutionalised for so many years.

> ***I had to 'own' the dream and vision for a good life for Cathy if I was going to be the person to drive it forward and I had to be the person to drive it forward as there was no one else in the driver's seat***

In some ways this could have been an easier option for me to believe, however, deep down in my spirit I knew that this was not true. Cathy was being denied an opportunity to live a good life that had purpose and enjoyment for her. Instead, Cathy was living a life that was segregated, isolated from family and friends, sitting waiting, waiting and more waiting. She had no say over who she lived with, who supported her, what her daily routine would be. Why should Cathy be viewed as 'different', 'the other' and ultimately denied a life of purpose and left to live out her days in an institution where none of us would like to live?

I discussed my dream of Cathy living in the community with so many people – my husband, brothers, sisters, friends, allies, advocates, community workers, bureaucrats, ministers as if it might happen by just talking about it. So many people had heard my story over the years. When I reflect back there were many wasted hours in just talking and not doing.

In the late 1990's some friends, my sister Carmel and I participated in a planning session with a work colleague acting as the facilitator. On reflection, although it was a great planning session what stopped me from going forward was my lack of belief that my dream and vision for Cathy could become a reality.

How did I turn the dream into reality? The turning point for me firstly, was to believe that Cathy deserved and had a right to have a good life that had purpose for her - a life that was crafted to give her great fulfilment and enjoyment - a life very different to the past 47 years. Secondly, I needed to believe myself that this was possible. There was no use riding on the backs of someone else's beliefs that my dream was possible. I had to 'own' the dream and vision for a good life for Cathy if I was going to be the person to drive it forward and I had to be the person to drive it forward as there was no one else in the driver's seat. *If the dream was to be it was up to me to make it happen.* For it to become a reality I had to focus and remain positive about what I believed and not allow distractions and negativity from others to get in the way. I had to have a shift in my thinking from 'things happen to Cathy' to intentionally making positive things happen for Cathy. I had to be that strong tenacious advocate that I was for so many other people with disability.

I also struggled with the notion of doing it all myself and I knew that it wouldn't happen unless I had a group of like-minded people around me who would walk the journey with me. It was difficult for me to ask people to be part of a circle of support, however, when I approached people and asked them to be a member of the support circle for Cathy people have responded very favourably.

The attendance at a six day workshop in 2007 gave me, Carmel and a small group of friends who had met and got to know Cathy an opportunity to think thoughtfully and respectfully about what a 'good life' would look like for her. It was here that I was also challenged to think about Cathy as a woman in her own right rather than a severely disabled woman. It was very important for me to be clear about my own values and beliefs about the place of people with disability, about the gifts and talents they bring and the contribution they can make to community. In this instance I needed to be clear that Cathy was no different to other people. Similarly, despite all those years in the institution she was no different to other people who live with a disability and no less deserving of living a good life.

Together, we spent time exploring who Cathy is, what she enjoys doing and what would give her life purpose. This was crucial so that our vision and plan for Cathy was developed around who she was, her gifts, abilities and talents and what she enjoyed doing rather than Cathy having to fit into what we developed for her.

We developed a strong vision statement that included Cathy living in her own home in the community, having family and friends around, paid and unpaid care and Cathy doing the things that she enjoys most. On reflection, it needed to be a vision that would stand the test of time and one that could not be watered down where Cathy got a lesser life. We developed two vision statements. One that we thought that Cathy would have for herself and the other was for family and friends to drive us forward.

The vision that we believed that Cathy would have for herself was drawn from family and friend's knowledge and understanding of Cathy's needs and wishes and is stated as follows:

To be around my family feeling loved and included, being clean and tidy, wearing nice clothes, with my hair looking good, and having choices.

Living in my own home with people with similar interests who I like, having fun and sharing a similar lifestyle.

Receiving good health care, enabling me to discover, explore and live my life to the full!

The vision to drive us forward in getting a good life for Cathy stated the following:

Cathy is surrounded by a network of family and friends.

She is loved and included and living in her own home, doing and choosing the things she loves to do, with strong secure (paid and unpaid care) and support.

Feeling her life is meaningful and that she has her place in the fabric of life.

With the vision developed, (one that we would regularly revisit and strengthen if warranted) we set about developing goals for some of the practical aspects of Cathy's life. These included home, relationships and friends, communication, health care, financial matters, decision-making, and safeguards.

It was too daunting to look at the overall picture of what needed to occur but these goals broke our plan down into bite size pieces

There are other aspects of life that we could have planned but it would have been too daunting a task to set in place. Instead we chose the aspects of life that we could influence and would enable Cathy to have a better quality of life whilst she was living in the institution. We set goals for the chosen aspects of life and went on to develop strategies for each of these.

It was very important to me that we set goals that were SMART - Specific, Meaningful, Achievable, Realistic and Time-bound. It was too daunting to look at the overall picture of what needed to occur but these goals broke our plan down into bite size pieces.

The plan was not set in concrete but needed to be developmental and flexible enough to adapt with changing circumstances which inevitably occurred. Although, this might prove challenging for me it is what assisted me in the long-term. It was more appealing and less intimidating - that worked for me.

It was crucial to be intentional about developing a plan because without one Cathy would have either ended up living her life out at the institution or living somewhere else not in her best interests. From my work experience as an individual advocate I was aware that I needed to be proactive and not just rely on the service system to meet Cathy's needs and keep her safe. It has been critical for me to develop strong safeguards to keep Cathy safe and the best safeguards have been to have unpaid relationships in her life.

Furthermore, I clearly understood that I should not wait for funding before developing a vision and plan for Cathy's life. This would have been too late. I have also learnt that funding can also contribute to Cathy's vulnerability and that an individual package with Cathy's name attached to it does not guarantee that Cathy gets the life that I had envisaged and planned for her. There is more work to be done to create a great life for Cathy.

The planning that we did for Cathy was not about planning that many services may ask people with disability and their families to participate in. This planning was about creating a 'good life' that has meaning for Cathy and one which she finds fulfilling - a life of purpose. No one asked us to do this. We took control and decided to do it. The service planning is often just about getting through audits and the requirements of service agenda and not really about creating a fulfilling life for the person with disability.

Cathy has a placard on her wheelchair which was given to her for a recent birthday by a close friend. "*God has a plan for my life. It is so far behind schedule I will never die*!" This means that we need to continue reviewing what is happening for Cathy and be prepared to make the necessary changes to ensure that the she has a great life now and into the future. For me personally, to achieve a great life for Cathy may take tears, time and enormous effort, be challenging, be fraught with hard and difficult discussions but I know as her twin sister she deserves the opportunity to have a good life doing the things that she enjoys most with people she chooses to have in her life - just as I have had.

Although, Cathy's life may well be richer than it was six months ago, we are not there yet - it is still in the making and will only happen by us being willing to challenge the status quo and be prepared to actively build a good life for Cathy.

This planning was about creating a 'good life' that has meaning for Cathy and one which she finds fulfilling – a life of purpose.

No one asked us to do this. We took control and decided to do it

Service Planning: Thinking, talking and believing what is possible Deborah Naughton

Deborah Naughton works for Community Connections in Townsville, Queensland. In her role as the Lifestyle Facilitator, she works with families and individuals on planning and skill building to assist them to create authentic lives in their community. Deborah entered the Disability Sector around 8 years ago when she moved to Australia. Before that she was working in Germany for the British Military of Defence, supporting army families to settle and adjust to living in a different country and culture.

In this article Deborah shares her insights about what is required to ensure a plan created between an individual and the service in their life will be effective in assisting them live the life they aspire to live.

Service Planning: Thinking, talking and believing what is possible

One thing I have learnt is that very few people have their lives mapped out on a piece of paper – their life plan. Yet having an opportunity to stop and think about what would make us happy and feel that we are living life to the fullest would be something most of us would appreciate.

It is good to remember that planning is just a tool that provides a framework for people to be clear about their goals in life and what it is they want to achieve.

In our small service the planning is individualised to suit the family culture, so planning differs from person to person. That being said, there are some common factors. We have face to face meetings to develop a rapport with people so they feel comfortable in talking about their personal dreams. We feel it is also important to invite family, friends and stakeholders who have an involvement in an individual's affairs and offer a lot of support in that area. We need good listening skills to interpret what is being discussed and through checking with them we can make sure we have correctly heard what has been said. We record the plan in a way which, as well as, helping develop strategies that address their goals and provide us with a starting point, also ensures we are building on existing supports and reflecting the needs and wishes of the person we are working with.

Everyone needs a way to start thinking about how they would like their life to look, so when we start working on a plan I like to offer different tools that suit that individual's needs.

Wendy is a woman I have been working with for a few years now, but when I started working with her on her plan she was overwhelmed and closed down. She had little if any control in her life, she had never really been asked what she wanted her life to look like.

We started by having some conversations about her goals but she was not really clear how her life could look. We used a number of different tools to get Wendy started and as she did not have anybody in her life to help her with her plan, the team at my office helped out. On the table we spread lots of photos of things that we all have that enrich our everyday lives. They were of people enjoying different social activities, different types of relationships, places and material objects. Each person chose around ten photos that had meaning to them and then we went round the table taking about what we had chosen and why. Some people wanted a holiday overseas some people wanted to try new hobbies.

Wendy chose five photos. She said she wanted a kitten, flowers in her garden, money, to learn how to knit and tell the time. She was not asking for very much and this reflected the modest dreams and vision she had for herself at that time.

> ***The richness of the plan comes when you can get a person thinking, talking and believing what is possible for them.***

Wendy went on to achieve her goals within six months so we revisited her plan. This time she created a visual collage which included a house on the beach, beautiful furniture to fill it with, an engagement ring, a wedding celebration and the groom. These types of modelling worked well for Wendy as they helped her to expand her vocabulary. She is becoming more able to articulate what she feels and she has a better understanding of social etiquette and of what other people feel about their lives.

We are now four years on and Wendy has little need for visual prompts when we review her plan and she is much more able to identify goals. Much of this has come from the confidence she gained from the smaller successes. These days Wendy still creates a visual collage using magazine cut outs and she tells me that it motivates her. I feel we would not have got such a successful outcome if we did not use a variety of different tools in the planning process. The richness of the plan comes when you can get a person thinking, talking and believing what is possible for them.

When creating a plan, it is beneficial to take a holistic approach to a person's life, as there are many factors that influence how successful a plan will be. A good example of this is a person's health, for if a person has undiagnosed health issues that are not being addressed this will have a negative effect on their ability to focus on the plan they have developed to achieve their goals.

Another lady I work with often missed out on swimming due to an upset stomach. We discovered she is lactose intolerant and now the connection had been made and she is avoiding dairy and is now attending swimming regularly which is greatly improving her quality of life.

I often work with people who do not have family or friends to offer them support in creating and implementing their plan. In this case there are sometimes legal stakeholders involved and it is important that they are also welcomed to work with the service and understand what that persons plan is about.

Wendy identified that she wanted to find a partner and get married. In this case it was very important to have a good relationship with legal stakeholders, such as the Pubic Guardian and the Public Trustee. By involving them in Wendy's plan and its challenges it has helped overcome some hurdles and created a safety net around her. This has allowed Wendy to have control and follow her dream but to have safeguards for herself and the service to limit the damage when she has made decisions that have not worked out well.

It is the opportunity to make these decisions that has allowed Wendy to learn, grown and mature. We have been lucky to have some continuity in the people that are Wendy's Public Guardian and Public Trustee officer as we have been able to build trust and work well together.

When starting to implement a plan there has to be some immediate progress. By including small achievable steps successes can be observed and celebrated early on and this gives immediate reward while providing an opportunity for the person to increase their skills

> ***Celebrating the small successes can make all the difference when you are working on long term plans***

Once the person has a few successes under their belt it is time to move on to the more difficult goals, but sometimes the timing is not right and we need to put that part of the plan on hold. When there has been a lot of change in a short period it is nice to let it gel allowing the person some time to get used to the changes and that is why it is good to keep reviewing the plan. Celebrating the small successes can make all the difference when you are working on long term plans. There are often two steps forward and three steps back, but it is the small celebrations that keep people motivated.

Life can often be chaotic and take many different directions. Due to this unpredictability it is important to be flexible and responsive to the person and to recognize what is going on for them. We have a yearly cycle for the plan but we review regularly as this can spark new ideas for some people. Not all plans stay on track and if someone's life takes a completely new direction we may have to start again.

Using Wendy's plan again as an example, we are still working together on achieving her goals, but they have become more complex as she has grown as a person.   Although some of the goals have been achieved in some ways, the plan has been revisited and re-written many times to reflect her changing life circumstances. These have included finding a partner and being in a loving relationship for over two years and then dealing with the breakdown of the relationship and the rebuilding of her life again as a single woman.

The reality is that there are some goals we cannot deliver for people, such as partners, relationships and family. It is important to acknowledge that these are important drivers in people's lives and to establish with the person what they can do to move towards these goals. This might include creating opportunities and building capacity in people to be in the right place, at the right time with the right skills. It is like planting a seed. By putting the seed in the most fertile soil with access to sun and water you have given it the best chance of germination.

It is as important to look back at what has been achieved as it is to look forward at what else can be done. It is crucial to revisit the plan to keep it relevant and useful. There also needs to be creativity in the interpretation of a person's goals, openness to opportunities to develop networks in the local community and an exploration of how the person can take up valued roles as this also increases a person's fulfilment.

You cannot expect a plan to run to your timescale it is all about the person and their journey. As a facilitator it is hard not to be pushing to achieve the next goal. I have had to learn to wait for when the person is ready to move forward and sometimes it has been years in the making. This is why it is important to keep reviewing the plan so you do not lose sight of the plan's focus. I believe the continuity of working with the same people over a long period of time has been beneficial, particularly in understanding the history of where the person has come from on their journey and to ensure that they are always moving forward at their own pace.

While having a plan gives a person hope, vision and direction in life, it should be a part of a person's life but not always take the main focus - it is something that is always there in the back ground. There are times when a person has achieved a goal that they have set but need time to consolidate, before moving on to the next thing.

I will leave the last words to Wendy. When I spoke to her about using her story in this article, I asked her how she felt about her life when we started working together. She said "it was crap".

I asked her how she felt about life now and what she thought about the planning process. She said she felt "good inside", "I've improved my skills and relationships" and that planning helps "you see clearly what you can do with your life".

> **You cannot expect a plan to run to your timescale it is all about the person and their journey… I have had to learn to wait for when the person is ready to move forward and sometimes it has been years in the making**

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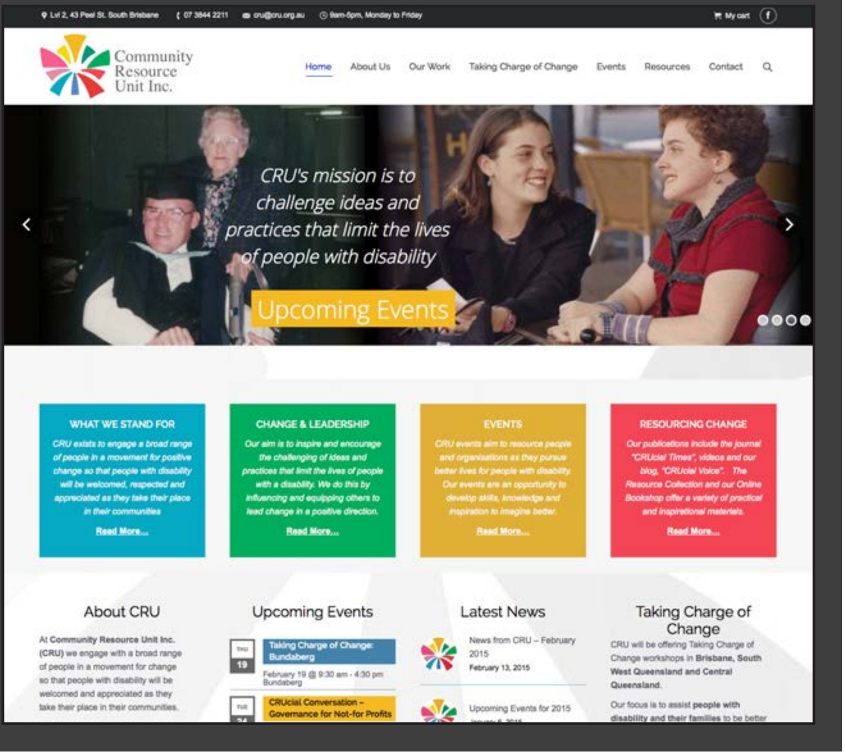

CRU's mission is to challenge ideas and practices that limit the lives of people with disability

WHAT WE STAND FOR

CRU exists to engage a broad range of people in a movement for positive change so that people with disability will be welcomed, respected and appreciated as they take their place in their communities

CHANGE & LEADERSHIP

Our aim is to inspire and encourage the challenging of ideas and practices that limit the lives of people with a disability. We do this by influencing and equipping others to lead change in a positive direction.

EVENTS

CRU events aim to resource people and organisations as they pursue better lives for people with disability. Our events are an opportunity to develop skills, knowledge and inspiration to imagine better

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Our publications include the journal "CRUcial Times", videos and our blog, "CRUcial Voice". The Resource Collection and our Online Bookshop offer a variety of practical and inspirational materials.

About CRU

At **Community Resource Unit Inc. (CRU)** we engage with a broad range of people in a movement for change so that people with disability will be welcomed and appreciated as they take their place in their communities.

Upcoming Events

THU 19 Taking Charge of Change: Bundaberg
February 19 @ 9:30 am - 4:30 pm
Bundaberg

TUE CRUcial Conversation – Governance for Not-for Profits

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News from CRU – February 2015
February 13, 2015

Upcoming Events for 2015

Taking Charge of Change

CRU will be offering Taking Charge of Change workshops in **Brisbane, South West Queensland and Central Queensland**.

Our focus is to assist **people with disability and their families** to be better