CRUCIAL TIMES

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Editorial: What do we mean by inclusion?

In 2017 it is not the norm for people with disability to be included in the general life of the community. Real inclusion can and does happen but is much rarer than it should be after decades of talk and having it as a stated goal in countless plans and endless documents. Most children are born included; they start life as part of a family and a neighbourhood or community. However, when the child or person has some difference, the rules change and their inclusion – their right to belong and be part of that family and community- changes. Being different is not the problem; but being treated differently simply because of that difference is.

Aspiring to inclusion, without a well thought out strategy to counter the blocks and barriers is not enough. Changing our own habits and the habits of the community requires a strategic approach. In this edition, our writers provide a rich range of strategies to assist us to work towards inclusion.

When trying to define something it's often useful to say what it is not; so we can say that being included in the community is more than just 'not being segregated in an institution'. Being present and visible is a good start but is not enough to be included. As Ann Greer says in her article, inclusion involves relationships, contribution, purpose and identity in a person's community.

We find ourselves now, not only with real inclusion being rare, but with many practices being called inclusion when they clearly are not. Unfortunately, placing the words Community or Inclusion in the name of a segregated group or activity is not enough to make it inclusive. In a desire to be tolerant we can sometimes think that it is okay to have a variety of options for people, some of which are more inclusive than others. However, it is useful to bear in mind Kathie Snow's perspective that "*any separate, parallel, segregated activity inadvertently sends harmful messages and, or reinforces prejudicial stereotypes: "they" (people with disabilities) don't belong, aren't good enough, should be with their own kind, and more. In addition, the apparent "success" of any separate program breeds more of the same, as others think this must be the "right thing to do."*

We find ourselves now, not only with real inclusion being rare, but with many practices being called inclusion when they clearly are not.

Segregated groups and separate activities often start when we, as supporters have low expectations of the person's right to be in their community and the contribution they can make when given a chance. Separate groups are often set up in an attempt at kindness; based on the belief that children should be able to experience ballet or basketball or school but that they will not be able to participate in the local existing groups and that their presence in those groups will slow down or hinder the progress of the other children. We are worried that the child with disability will be teased or bullied. We tell ourselves and each other that community is not safe and that people are cruel. All of that can be true however opting for the false 'safety' of separateness and invisibility is not the answer. The energy and resources it takes to set up a separate world could be better directed to supports and safety nets in the community. As Peter Gregory says in his article, exclusion occurs when we make excuses for why inclusion is not possible.

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Editorial Margaret Rodgers, Chief Executive Officer

The alternative is to assume that the person belongs and will be present in their local places. Evidence shows when this message is communicated confidently more people than we might expect will accept that point of view and welcome the person. Ann Greer observes that most people are very happy to see people with disability present but they are not proactive in being welcoming towards them. She also suggests that some information on how people can be helpful equips them to be more welcoming.

People with disability do not learn better, are not necessarily happier and certainly not safer when they spend their lives in separate activities. There is also a lot of evidence including by our writers in this edition, of the increased happiness and self-confidence of people with disability who know they belong. In her article Deanna Parker talks about the changes she observed when the person she supported was included in the local school. We need to remember that the things that make life good for people – acceptance, belonging, love, meaning - are the same whether you have a disability or not. Rob and Virginia Lonsdale describe how the local scout groups welcomed their son but also served as a launching pad to other local community connections.

We are not talking about situations where people with disability choose to spend time with friends who also have disability who have shared life experiences, interests and hobbies. As Kathie Snow says ‘ *the issue is when we create separate, parallel, segregated activities and call these inclusive; and in the process, exclude people with disabilities from ordinary and truly inclusive activities*’

As supporters, when we find a welcoming place in community, it can be tempting to want to direct everyone with a disability to that place, thereby compromising the experience for everyone concerned. Kathie Snow shares the idea of natural proportion as a litmus test of inclusion. She suggests that an inclusive environment is one that reflects the “natural proportion” of people with disabilities in our society, so if the percentage of people with disabilities is greater than the natural proportion in any environment or activity, it is not inclusive; it represents an artificial environment.

With this in mind, we need to understand our role as families; friends and workers, as we ‘ask’ on behalf of a person and our writers have useful reflections on this. Our writers recommend starting, or staying, in the local and ordinary world when children are young as everyone is learning about where people belong at that stage. It’s important for the child with disability but equally important learning for children who don’t have a disability. In their article, Virginia and Rob Lonsdale are clearly very thoughtful and strategic about what they want for their seven year old son and how they can help him to be known and valued at school, in the neighbourhood and at Scouts.

We have grown up in a world which has normalised the segregation of people with disability and denied us all the opportunity for relationships to develop. We need to learn to think differently if we are to counter this. The general community is not accustomed to welcoming people with disability, so our role of inviting them into relationship is a critical one.

Our writers also note that our workforce needs to change to support people to be included. As a service manager, Ann Greer reflects that when supporters portray the person they support as needy and deficient, rather than attractive and competent, it denies the community the opportunity to see people with disabilities as gifted, talented and attractive human beings. She recommends supporters look at the person’s strengths, passions and interests and use those as the platform to ask on behalf of the person with disability. Deanna Parker recognises the volume and value of preparatory work needed to increase the chances of success but cautions against waiting for the perfect time. Her article also reinforces the importance of having people work together.

Peter Gregory highlights the need for supporters to understand the organisational blocks to inclusion and to reflect on their role in this – whether as a support worker or manager or even as a family member.

As we reflect on what each of us can do to make the promise of inclusion a reality for all people with disability, this edition of CRUcial Times reminds us that it won’t just happen. It requires more than us just liking the idea of inclusion and hoping it will eventually happen. Reversing the habit of exclusion will require each one of us to be very clear, strategic and thoughtful about who we ask, how we ask and what we ask for.

Margaret Rodgers
Chief Executive Officer

From the Committee Sherryn West

From the Committee

Inclusion matters. This is a message shouted loud and clear for many decades from people with many different backgrounds – CRU even held a conference on this topic in 2012. Fast forward to 2017 and this edition aims to continue this call and demonstrate the change we need to embody.

In the words of Greg Mackay (CRUcial Times 47), “in the absence of a decent conceptual framework, people rely on habit and history”. The problem here is we have many habits and history that need to change and this is just one. Society has a history of excluding many; not just people with a disability! Slowly, we are changing the habit but we all know it takes time to change and we don’t always succeed. We have to keep trying and with each attempt we gather that little bit more wisdom along the way in the hope that next time we succeed. This is important work for as Buddhist teacher Pema Chodron said “The slightest willingness to interrupt our old habits predisposes us to greater bravery, greater strength, and greater empathy for others.”

I reflect on my own sister’s experience. She is now thirty something and living in a home of her own. She has support to assist her to find her passion, to create relationships and to have a meaningful connection with her community. It takes time and it is often challenging; not because she has to change her habits, but because she has to change everyone else’s and that is hard work! Slowly she is creating her own history of inclusion and as she brings along other people on her journey she is changing their habits as well.

We hope that at CRU we can facilitate the creating and sharing of those habit and history changes! As we implement our next strategic plan we will seek to stay true to our core values and vision, focused on the challenge of genuine inclusion for people living with disability. CRU will enact this strategy through various workshops, information sessions, publishing CRUcial times and sharing the wisdom of others in ‘Bringing the Good Life to Life’.

We hope you can join us as we work for a more inclusive world.

Sherryn West
Treasurer

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It is so close that you can touch it...

Ann Greer

Ann Greer is the Manager of Community Connection in Townsville, an organisation she helped to establish in the early 1990s. Community Connection was established to provide individual customised support for people with disability to build a good life based on full and valued participation in community.

Ann has particular skills in the areas of behavioural strategies, communication and lifestyle planning and she is also the mother of 3 adults, two of whom live with disability. She has a long history of working to promote community inclusion as both a family member and worker, including with people at particular risk of community exclusion.

It is so close that you can touch it and smell it so why aren't people with disability able to pierce the membrane into community?

When we are working on achieving the inclusion of people with disabilities into the community, it appears that we have a very narrow idea of what needs to happen to make this a possibility. In the past 25 years, we have moved from an isolating, institutionalising model of support into one that maximises presence in community but we have not been as successful in achieving full participation. There are many reasons why this is so, but a lack of understanding by all key stakeholders on how community works is a major reason.

True inclusion is to belong and to belong is more than presence. It involves relationships, contribution, purpose and identity in a person's community. To maximise this and to form a fertile bed for friendships to grow between people with disabilities and other community members we will need to understand the world we live in. We need to consider the quality of the support provided and the barriers that are created by people with disabilities and their families. We need to acknowledge and challenge the overt and covert barriers created by a community that de-values people with disabilities. We also need to understand how the systemic segregation that starts when children are young further ostracises people with disability, leaving the community socially inept when confronted by any difference.

Services have largely been created to support the deficits of people with disabilities – to do for the person what he or she can't do for themselves. This deficit based model does not expect or create the necessary skills in its workforce to truly support people to a life in community. Many services are risk averse and rarely 'colour outside the lines'. This leaves the people they support isolated in a world of paid companionship with few opportunities to meet people outside of this world. It also denies the community the opportunity to see people with disabilities as gifted, talented and attractive human beings, rather than someone who is inherently needy and deficient.

Families, people with disabilities and service providers need to be aware how seriously this style of service negatively affects the quality of life and opportunities of the individual supported.

Some families will have to re-think their approach to rearing a child with a disability. By parenting in such a way that the child never grows into an adult they miss the opportunity to take risks or make mistakes in the way that brothers and sisters do.

> ***We need to acknowledge and challenge the overt and covert barriers created by a community that de-values people with disabilities. We also need to understand how the systemic segregation that starts when children are young further ostracises people with disability, leaving the community socially inept when confronted by any difference.***

Ironically this protection for a perceived vulnerability, has left many people with disabilities profoundly vulnerable.

Ironically this protection for a perceived vulnerability, has left many people with disabilities profoundly vulnerable. A life lived on the periphery of community, for example not going to church with the rest of the family, not going to school with your brothers and sisters, not getting the chance to experiment sexually or spiritually, not having work or other valued roles is not a template for a full, happy, well connected life.

This is not a judgement on these families, many of whom have shown incredible depths of commitment to their children with disabilities. This is an observation of the profoundly negative fall-out that results when people are seen not as fully human, but as different and 'other'. In other words, when 'the good life' in community for a person with disabilities does not mean the same thing as for other community members.

After living life on the sidelines, held to ransom by practices that keep people congregated, some people with disabilities will also need to rethink their expectations about their lives and be prepared to show courage by stepping out into community. Many people with disabilities talk about the isolation they feel but will opt for what is known rather than what is not known. The disability community for all its imperfections is a known factor. Opting for a life where you have to 'put yourself out there' is decidedly unknown and therefore frightening and off-putting for some individuals and their families. Many people will need to learn about what is expected of community members. A life of segregation does not prepare people for this but it does not mean that people with disabilities cannot learn these skills - the question is more about who will teach, model and mentor?

Local Quality Assurance auditors HDAA are from New Zealand and they use a wonderful Maori saying as the banner for their business. It states:-

> *When we ask 'what is important?' Proclaim it to the land;*
> *proclaim it to the sea….. it is people, it is people, it is people.*

Activities performed in a bubble, where any contact with community members is superficial, rarely – if ever – leads to a deeper relationship. The transition from this 'client' mentality to a more holistic support to the individual – one that supports the whole person – will be complex for services that maintain a pool of workers and who do not invest in the necessary time and space required for meaningful relationships to develop between the worker and individual who requires assistance.

Human Services can also do a lot to foster the inclusion of people with disability in community. This can be done by:

- **Building a true appreciation and understanding of what a genuinely inclusive educational experience can do for the student with a disability AND the school community.** This is a major step for ensuring an inclusive society in the future and if we don't get this right, we will be doomed to puzzling about how to get people included for generations to come.
- **Starting from the point of the person's strengths and passions.** This will make it easier to understand where we should put our attention when we are trying to find a place or space for the person supported.
- **Building a deep belief in the rightness of people with disability living and playing in our shared spaces.** This will assist us to continue working on this, even when the going gets tough.
- **Understanding that community is not a perfect place.** We must pay attention to what makes the person with a disability vulnerable and to build supports around him or her to minimise that vulnerability.
- **Employing competent and engaging people with good judgement and social skills and who understand their role.** This will go a long way to building a network around the person.
- **Understanding that a positive image for the person with disability is paramount.** As well as helping an individual to build a positive self-image, it is vital others see them in a positive way. Key to this is being mindful about how that individual is dressed, what he or she is doing, how supporters are relating to him or her and to the general community. When these concepts are attended to, it becomes much easier to find a place for the person with a disability in the community. Social Role Valorization (SRV) offers a framework that shows how this is done.

- **It is crucial that we let go of the heavy investment in congregation for people with disabilities.** These settings are a barrier to inclusion and are counterproductive to the concept of positive image, growth and development and valued social roles. Families are often drawn to them because they have concerns about community and it is fair to say that we have not been as successful as we need to be in achieving a full and connected life for many people with disabilities. It is concerning to hear many families of younger children talk about the lack of welcome and the level of judgement that they feel when in community and that many families of young children are opting for the 'safety' of congregation. This is a false sense of safety which uses resources that would be better invested in community to help find a space for people with disabilities.
- **Thinking and working creatively and opportunistically is a major aspect of this new world.** It will require all stakeholders to think outside the box when it comes to what the individual will be doing with his or her time from day to day. Neil Barringham[1] talks about finding the 'sweet spot'. The sweet spot is that moment when you identify that a real connection has been made between two people. In the case of people with disability, it will often rely on what happens next – what those supporting the individual do - if the embryonic opportunity is to grow into a relationship.

It is also true that community has been inept in its approach to people with disability. There has been a profound change in the way that people with disabilities are seen by the general community. Most people are very happy to see people with disability present but they are not proactive in being welcoming towards them. The major reason for this is that society is generally very puzzled about how to welcome people in. For some it is due to the belief that people with disabilities are happier 'with their own' while others are nervous and unsure how to communicate or relate to people perceived to be 'different'. This is a major outcome of a segregated school system that gives very clear messages about the proper place for devalued people. The education provided by schooling needs to be seen as a much wider concept than just an academic one for society. A truly inclusive educational environment can be a hotbed for personal growth and a solid foundation for the development of healthy communities.

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There are no recipes to ensure that people with disabilities can take their rightful place in community – no method that says 'first do this, then do that'. Friendships for people with disabilities cannot be created by others – not parents, not siblings and not support workers and their employers. However, because friendship sparks from chemistry, there is still much we can do to create opportunities for people to truly get to know each other and thus it is our role to create a fertile bed for relationships to grow.

When I think of the people I know for whom inclusion has been a living reality it is clear that the criteria for success is not obvious competence. These opportunities happened because an individual saw an opportunity and did what is called 'not waiting - creating'[2] . They looked at the person's strengths, passions and interests and used those as the platform to ask on behalf of the person with disability. This does not rely on funding. The person who asked, believed in the attractiveness and competence of the person they were asking on behalf of and they took the action necessary to move an opportunity into reality. This is the kind of platform of support that is necessary to move people with disability from a life of isolation and 'activities' to a life that ensures that he or she is a valued, loved and recognised member of our community.

[1] Neil Barringham is the manager of 'A Place to Belong' in Brisbane and is the author of "Finding People to Be There: Rebuilding a sense of belonging'.

[2] Margaret Rodgers. "Not waiting – Creating'. CRUcial Times 29, March 2004.

What is Inclusion? What's not?

Kathie Snow

Kathie Snow lives in Texas, USA, and is the parent of two young adults; her son, Benjamin, has a disability and recently earned his Master's degree. Before the births of her children, she was a broadcast television writer, producer, and director and a print journalist. She combines her earlier career in the media with personal experiences in the disability arena to ignite positive and long-lasting change.

Kathie is the author of Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities (now in its third edition) amongst other influential resources. She also presents keynotes and workshops at international, national, and state conferences; provides day-long trainings for parent groups, schools, and human service agencies; and has coordinated conferences and developed training curriculum.

What is Inclusion? Why are more people concerned about it? And why now?

Let's start with the last question. Some of us have been agitating for the inclusion of children and adults with disabilities in all areas of society for many years. (In my case, for 24 years, after my son, Benjamin, was diagnosed with cerebral palsy shortly after birth.) At that time, some people saw inclusion as a fad—the "wild" idea of "radical" parents—that would pass. But it wasn't and it didn't.

Why are some people concerned about inclusion? For many reasons, in no particular order. Because some parents want the same life for their children with disabilities that their children without disabilities have. Because some people embrace the spirit and intent of federal laws (Developmental Disabilities Act, Individuals with Disabilities Education Act, Americans with Disabilities Act, and others) that affirm the full participation of people with disabilities in all areas of society and/or prohibit discrimination based on disability. Because some people recognize that the invisibility of people with disabilities (in schools, community activities, employment, etc.) is *not* the result of one's *choice* to be invisible, but the outcome of systemic efforts by others to "help" people that resulted in segregation in special, separate programs. Because some people with disabilities and/or their families are refusing to accept segregation. Many people recognize the abject immorality of segregating, devaluing, and marginalizing people based on a characteristic—inclusion represents the polar opposite of institutionalizing people with disabilities, a practice that represented conventional wisdom for decades. (The 1954 Supreme Court decision in *Brown v. Board of Education* is unequivocal: "Segregated facilities are inherently unequal.")

So inclusion—in schools, communities, employment, and other places—is a hot topic for some. But many activities that are *described* as inclusive are not! (And some people use the terms "mainstreaming," "integration," and "inclusion" interchangeably, but they're not the same. See my article on that issue at www.disabilityisnatural.com/images/PDF/mainstream.pdf.)

It's estimated that 20 percent of adults and 10 percent of children have medical diagnoses that are categorized as disabilities. Those numbers represent the "natural proportion" of people with disabilities in our society. An inclusive environment is one that replicates the natural proportion. So in a classroom of 20 students, for example, there should be no more than two students with disabilities (10 percent). If the percentage of people with disabilities is greater than the natural proportion in any environment or activity, it is not inclusive; it represents an artificial environment. Inclusion means all people, in all environments, all the time; or as others have simply and eloquently said, "All means all."

When we label something as inclusive but it's *not* (because it does not reflect the natural proportion), this doesn't simply represent a misuse of language; there can be harmful consequences, not only for people with disabilities, but for our society, as well. Let's look at some examples before going further.

A school principal says his school is inclusive because students with disabilities are *in the building* (but are isolated in "that room" at the end of the hallway). They don't participate in any way with students who do not have dis-abilities. Physical proximity is inclusion, in the mind of the principal (but it's not).

Someone shared info about an "inclusive cheerleading program for disabled girls" (their words, not mine). If it's "for disabled girls" then it's not inclusive. In this "program," girls with disabilities were not part of the school's "regular" cheerleading squad; they were members of a parallel (separate) squad just for girls with disabilities. This is not inclusion. Could high school girls without *disabilities* join this group? No.

Human service agencies provide disability services that are mandated by state and federal laws. Their programs (funded by tax dollars) are, by their nature, special and segregated since people *without* disabilities are not eligible for these programs. Some agencies are now promoting "community inclusion" activities: separate recreational programs (including Special Olympics), dances only for adults with disabilities who receive services, etc. These may be located "in the community" (as opposed to an institution), but they do not represent "community inclusion"—people without disabilities are not participants.

Organized religion is not immune. (Christians might ask, "What *would* Jesus do?" I don't recall segregation of people with disabilities in the Bible—just the opposite.) "Special needs" programs for children and/or adults with disabilities are often the norm, but the religious entity considers itself inclusive. Examples abound in other areas of society—child care/preschools, recreational activities, clubs, separate proms at high schools, and more—that claim to be inclusive, but are not.

Finally, special, separate college programs have been created for students with disabilities that essentially replicate the segregated life-skills classes of public schools. These are called inclusive, but are not. Students *without* disabilities are not in these classes.

What are the outcomes when well-intentioned people *believe* their actions are progressive, but they're actually regressive? Any separate, parallel, segregated activity inadvertently sends harmful messages and/or reinforces prejudicial stereotypes: "they" (people with disabilities) don't belong, aren't good enough, should be with their own kind, and more. In addition, the apparent "success" of any separate program breeds more of the same, as others think this must be the "right thing to do." The marginalization, devaluation, and isolation of people with disabilities continues. Those who promote separate, segregated activities as inclusive pat themselves on the back for their good deeds. People with disabilities are supposed to feel grateful that they're "allowed" to participate. The dangerous "us/them" mentality continues; social justice, equality, and true inclusion remain an elusive dream.

We would never allow this for other populations. Would a predominantly "white" school create a separate, parallel cheerleading squad for African-American girls? Or vice-versa: would a predominantly "black" school sanction a separate program for "white" students? Would a college authorize a separate, parallel classroom only for students from the LGBT community? Think of other examples.

The issue *is not* whether people choose to self-segregate. We routinely join with others like ourselves based on shared interests: hobby clubs, park and rec activities, etc. The issue is when we create separate, parallel, segregated activities and call these inclusive; and in the process, exclude people with disabilities from ordinary and truly inclusive activities.

Instead of creating a special cheerleading squad, sports activity, or anything else, why not modify the "rules" to allow participation by all? That's what happened when the U.S. military and professional sports were racially-integrated in the 1940s, when women's military opportunities were expanded in the 1970s, and so forth. Again, think of other examples. If a group doesn't want to alter the competitive nature of its activity, for example, we can create a non-competitive, inclusive activity for all. Many families would like their children (*with and without* disabilities) to be in inclusive activities where one's participation is *not* dependent solely on skill level.

People with disabilities and/or families bear some responsibility for this situation. If, for example, parents didn't *allow* their children with disabilities to participate in segregated activities, they'd "go out of business." Hegemony is at work [from www.wiktionary.org]: "Dominance of one social group over another, such that the ruling group acquires some degree of consent from the subordinate..."

Knowing what's inclusive is simple: is the activity open to all and does it reflect the natural proportion (no more than 20 percent adults with disabilities and/or 10 percent children with disabilities)? Let's not use words like "inclusive" to mask segregation and/or to make ourselves feel or look good. Our fellow citizens who happen to have disabilities deserve better.

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Foundations for a good life

Rob and Virginia Lonsdale

Rob and Virginia Lonsdale are the parents of two boys. After a youth spent living and working around the world, they are committed to investing in their local community and ensuring that Elijah, who has a disability, has the same opportunities as his brother Thomas.

In this article they explore how their family is consciously building a foundation for Elijah to be included in community. Virginia and Rob's understanding on how to make a good life for Elijah is underpinned by the theory of Social Role Valorisation (SRV) and conversations with local parent leaders, courses at CRU, and through some time spent with Queensland Parents for People with a Disability (QPPD).

Foundations for a good life

VIRGINIA: In becoming a parent, I was hit with the overwhelming realisation that my own best interests now encompassed the best interests of our child. It was a stunning vista on the interconnectedness of our lives, but the ground below my feet also shuddered with the enormity of the responsibility.

This insight is particularly relevant for our child, Elijah, who could suffer or thrive for his dependency on us and our attitudes towards his ability to live in the world without being excluded, segregated or limited. For as certain as we are that there are many socially constructed impediments, parents also contribute to the size of their child's natural interaction with the world. Thus, we felt our enormous responsibility to listen and respond carefully to the question, 'in whose best interests?'. 'In whose best interests do these boundaries exist? In whose best interests are these activities undertaken?'

Our attitude about the absolute right for Elijah to belong just as anyone else does arises from this simple knowing – that Elijah is here on this Earth for his own reasons, that his life is of immense value, that he is whole and therefore complete and perfect as he is, and that he is loved, lovable and a lover of many things. Like me, his father and brother, he thrives on love, respect, attention, a bit of leeway, friendships, and a whole lot of fun. His inclusion may require, at times, a bit of imagination, planning, spontaneity or risk-taking, but if we can offer that, then I feel we are ethically obliged to do so - for the sake of love, empathy, and our dependency on each other. Moreover, Elijah's dependency on us, his parents, to build the foundations of a good life for him behoves us to think and plan about the causes that lead to a good life.

> ***Mostly, a life is created out of many small acts that contribute to the whole. Our focus then is to nourish the conditions and causes that can grow into the life that exhibits the characteristics listed above.***

As parents, we discussed what we would like for Elijah:

- To develop friendships, joy, play and spontaneity.
- To use his strengths, assets and gifts.
- To explore his interests, potentials and choices.
- To have adaptations to help with difficulties.
- To be known and to be understood.
- To develop competence and independence.
- To develop into a decision-maker in his own life.
- To be educated, to continue learning, to have a job, to have a partner, to live in his own house, to get around town.
- To be HAPPY, SAFE, and find meaning in his life.

These are, essentially, the same aspirations we have for our older son, Thomas.

Mostly, a life is created out of many small acts that contribute to the whole. Our focus then is to nourish the conditions and causes that can grow into the life that exhibits the characteristics listed above.

In its regular habitual flow, life gives us many opportunities to make connections with community through our daily tasks and travels. We regularly visit our local library, supermarkets, and the video store. It is truly uplifting to go into our regular places and feel welcomed. It's an important value of mine to acknowledge the person who is serving me in a way that is friendly, open and inquisitive, and I am keen to develop that life-skill in my children also. We get to know one another by making small talk, giving a smile, having a joke and over time relationships develop. For example, before we pop into the library, I suggest how Elijah could say hello, hand over the card and ask to borrow a book. At the video store, Elijah says hello and asks for directions to his favourite DVDs. The supermarket, also, has been a place where we always see a friendly face and have a chat. I always make sure to use people's names and that people know Elijah's name. Elijah watches and he has learnt how to ask questions and find ways to talk with people. Elijah helps out at the tills, packing our groceries, and taking instructions from the person at the checkout. All the time he is learning useful social language and mores that make a community civil and an enjoyable, simple place to connect with each other. A place where we can experience belonging.

At the age of seven school is,of course, a regular place. Elijah has a natural ability to remember people's names and so he knows the groundsmen by name and most mornings we have a chat with them on the way to the classroom. He also knows the names of the office staff and teachers and he always says hello to the parents of his friends. This has helped him become well known in the school and there are people who look out for him; people who are happy to see him. His day starts off with many warm welcomes. What I can add to that natural ability is lots of encouragement.

For me, there are many times in life where we can step up to the plate and become bigger, wiser, kinder, better people than we would otherwise know or believe ourselves to be. It can be such a simple step to adapt, be flexible, be positive, and see the humour in whatever is happening right now. Imagination, fun and risk-taking are often frowned upon in our drive for an efficient society, but the question raises itself, 'in whose best interests?' We believe a good-life is always the life SUITED TO THE PERSON, so whatever is a good fit for Elijah will be our guide.

ROB: Early on in Elijah's childhood we reflected on what could contribute to growing a good life for our little boy. As parents, we thought it was important for him to have lots of fun, make friends, and learn the skills to communicate with a variety of people. And, as such, we have been looking to nourish these things in Elijah's everyday life in the most regular and ordinary ways.

From the age of 2, I took Elijah every week to Scouts with his older brother, Thomas. At first it was to give his mother a break and to let Elijah do something with Thomas, but I soon realised that Scouts would provide Elijah with a great community. All the older kids and their parents got to know him. He would play and engage with everyone, dishing out high fives, having fun, showing off whatever he had just mastered. They saw his journey learning to walk and he mastered his first step up to the Den, to the cheers of everyone. Elijah helped me give a talk on Key Word Signing to the group, teaching everyone a bunch of signs. The Scout Leader, Possum, who still knows how to sign 'Chocolate', always had a Freddo frog for him.

When Elijah started at school, the connections he had already made paid off. The kids from Scouts were scattered throughout the years and classes, so walking around in the first term I would often hear "Elijah!" as someone called out to him. The friends they were walking with, not wanting to be left out of this special relationship, would get to know Elijah too. He was so happy to see people and engage with them that any 'disability' tag from being 'that kid who looks different' was quickly replaced by a name – "It's Elijah!" Last year Elijah was old enough to join Scouts. It was never a question of 'if' he would join, but 'when'.

In addition to birthday parties, Virginia and I decided that we would also have an end of year party to bring Elijah's friends from school together. We choose games that Elijah can take part in and all the usual party stuff. It's an easy way for Elijah to strengthen friendships and for us to get to know the parents. Everyone loves a party!

We have also started an inaugural vegetable growing competition with our neighbours' children. We all grow pumpkins, cucumbers, lettuces and other produce. We take photos and share our progress and then the plan is to have a 'best produce' party and cook-off, sharing all our delicious food. In doing this, we all become more familiar with each other and find a way to enjoy each other's company, along with all the skills we learn from growing our own food.

Expecting Elijah to communicate politely and to develop communication skills has been something we have encouraged from an early age. We started with signing, then an electronic communication-voice device, then speech, and now reading. Books have played a large role in helping Elijah. Reading is a valued skill, so we aimed to build on Elijah's good memory by focusing on sight words from an early age and as an added bonus it gave him something to WOW his teachers with. We filmed him for the school interview and showed his high-speed word recognition to the teachers, highlighting what a capable learner he was.

Book-reading is rewarded in school with certificates for students who have read 50 books and 100 books. We targeted this to get him on stage and have his name announced to the school assembly. He now proudly displays two Silver and two Gold reading awards on his wall, next to the Premier's 2016 Reading Challenge award. We have also always encouraged him to help us around the house with cleaning, sorting laundry, cooking or gardening, which he is keen to do. We have made photo books for him to take to school and share his home activities, which his friends always love to read. We try to show him being independent to reinforce his ability in his friends' minds. We practise reading these so that Elijah can read them to his friends at school. This puts him at the centre, making use of his reading skills.

> ***What I know for sure is that we as parents have to lead the way, by having the courage to set the highest possible expectations and, with an unwavering optimism, let our kids give it a go.***

Overall, I believe that our role as parents is to help lay a solid foundation for Elijah's future. The skills for communicating and being a friend, and the network within the community that we help him build will support him throughout his life and allow him to grow and thrive. What I know for sure is that we as parents have to lead the way, by having the courage to set the highest possible expectations and, with an unwavering optimism, let our kids give it a go.

NEW WEBSITE www.thegoodlife.cru.org.au

Bringing the good life to life

CRU
Expanding Ideas; Creating Change

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

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**

Whose Inclusion is it anyway?

Peter Gregory

Peter Gregory has been involved in the lives of people with disability in Queensland since the 1970's. As a young worker he became involved in the disability rights movement of the 70's and 80's that saw strong advocacy for the closure of large State run institutions.

His work with like-minded people, exploring how to put the ideas of self-direction and self-management into action, was a fantastic grounding for what is now being delivered by the NDIS. Coupled with a background in community development, Peter believes we have lost sight of the reality that people and relationships lie at the core of successful inclusion for those who sit on the margins. Beautifully constructed buildings, quality improvement plans and technological innovations cannot replace an open and welcoming community that recognises that diversity is the key to its continued health and vitality.

Whose Inclusion is it anyway?

The notion of inclusion for people with disability has been enunciated and pondered but not fully grasped for over four decades. This is a word with big expectations attached: a promise made that describes an expedition that is nowhere near its end, nor is it close to being fully realised. Amongst many other things, I am intrigued by what specialist disability support organisations can do to support inclusion, the role that support workers could play in supporting genuine inclusion and how could managers facilitate this?

My mind turns to the wisdom of a colleague; a person whose labels of profound intellectual disability, autism, non-verbal and challenging behaviour form the bingo card of justifications as to why exclusion is automatic and justified. During a conversation of profound enlightenment my colleague tells me that he is already aware of his intelligence, but others are not. In order for that intelligence to be revealed and enacted he requires others to accept and believe in his innate humanity, wisdom and capacity. He needs them to look beyond what they see to what they do not; he needs them to change their own behaviour towards him so that they can play their part in supporting his expression of "self". This is a profound concept that lies at the core of inclusion; my colleague cannot be who he wants to be without the world around him being willing to accept that he is not who he appears to be and, in accepting that, become so compelled by that reality that they set about changing their behaviour so that he is no longer the "other" and excluded.

Inclusion will occur when those in the world around a disabled person choose to change their behaviour rather than requiring the disabled person to change.

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What could a manager do to support inclusion?

It is not possible to guide others if your own beliefs and practices do not support inclusion. Therefore it is important to remember that you cannot mentor others about inclusion until your own practice is inclusive.

It is easy to state the belief that all people with disabilities, irrespective of the level of support they require, can participate and contribute to the life of their community but it is much harder to provide support in a way that make this a reality. This is why you need to be clear about what you believe and reflect on whether your actions enhance or diminish the inclusion of those supported by your organisation.

For the people you are connected with, can you answer yes to the following questions: Do they choose their own support team? Choose what support they receive and who provides it to them? Did they decide who they live with and where? Do they make all the decisions about what they do and who they do it with?

If you are answering "no", then ask yourself "why?" If your answer is "They have a disability and can't do this" then challenge yourself with the reflection question “What would I need to do right now to change that ‘no’ to a ‘yes’?” After all, exclusion occurs when we make excuses for why inclusion is not possible.

Thinking about the Support Worker role

It is equally helpful for people coming to the role of “supporter” to have the opportunity to reflect on their own beliefs and attitudes and how these influence the work they do. By offering simple exercises you can assist the support person to enunciate the beliefs and perspectives they bring to their role. For example, have them write a short narrative describing what they believe is the purpose of support in the life of a person and what has influenced these beliefs. Compare this with the fundamental principles of the Convention on the Rights of People with Disabilities, the objectives of the National Disability Insurance Scheme and anti-discrimination law. These documents offer a further means of contrasting personal beliefs with what contemporary service delivery and disability rights advocates are aiming to achieve.

Support workers come to their role for many and varied reasons and with very different experiences. They have usually also been brought up in a culture that has predominantly excluded people with disabilities through its practices, structures, policies and attitudes. If they are to support someone towards genuine inclusion then these beliefs, and the negative stereotypes that flow from them, need to be challenged, fractured and dismissed.

It is very easy to make assumptions about the support a person requires. It is also very common to label the things people do as “challenging behaviours” or “disruptive and anti-social” if they do not fit our assumptions of how people should be. Without even thinking the parent who asks lots of questions or has high expectations is dismissed as a “difficult parent” or “unreasonable. These are the attitudes that lead inexorably to exclusion and are used as justification to deny individuals their fundamental rights. These attitudes must be exposed within support teams or they will flourish into the support workers believing they are the experts in the life of a person, not the person themselves and their family. To break down this tendency it is useful for support teams to reflect on what may have brought individuals or their families to the point where they act in particular ways. It is equally important that families and individuals have the opportunity to tell the story of events that has brought them to this particular support setting and to describe exactly what they require from their support team.

What structures will make this possible?

In order to look at what structures make inclusion possible, it is important to acknowledge the many things that get in the way of exploring opportunities for inclusion. There are strongly held beliefs that full inclusion is not possible for all citizens with disabilities. There are the assumptions that are made about what is in the person’s best interest. There is a paucity of inclusive practice that aims to create pathways into mainstream community life that can be referenced as a guide. There are also organisational structures, policies, procedures and activities that become more important than exploring opportunities for inclusion.

Try this exercise with your support teams. Describe in detail “What is the purpose of support in the life of a person with a disability?” List all the functions you believe are integral to the role of support worker. Now, make a list of what actually happens from the start of a shift to its end. List everything that the support worker actually does, not what you believe they do. Now analyse the two lists. Are they the same? If they are not the same, how are they different? What activities dominate in the “ideal” support worker role list? What activities dominate in the “What we actually do” list. Now ask “What activities do we need to do away with so that we can focus on supporting opportunities for inclusion? What does this tell us about the structures that need to be changed so that our organisation has a focus on very personalised, individualised and community centred support?”

A time for reflection

Having thought about your role as a support worker, a manager or a specialist disability support organisation assisting a person with a disability to explore opportunities for full inclusion, you might like to reflect on the extent to which this has occurred by asking questions such as these:

“As a result of my individual actions, and through my collaboration with others, has social and economic participation become a reality for the people who purchase the support I provide? Do they have:

- Increased access to their own accommodation?
- Increased access to educational opportunities?
- Increased access to paid employment?
- Increased access leisure and creative activities?
- Increased access to high quality medical care and nutrition?
- Increased financial security and independence?
- Increased opportunities for leadership?
- Increased opportunities to make decisions themselves and with their peers?
- Increased opportunities to self-advocate?
- Reduced dependency on specialist disability services?

The current changes to legislation and funding in Australia (through the National Disability Insurance Scheme) provide an opportunity for specialist disability support providers and their employees to critically rethink the role they play in the lives of people with disabilities. Continuing the practices of the past is no longer an option. How to support people experience full citizenship is the challenge for the future…

Supporting an experience of Inclusion

Deanna Parker

Deanna Parker currently works as a teacher's aide. She has been closely involved with Luke & his family for the last 6 years; assisting Luke's "inclusion" from Years 7 through to 12 at Coorparoo Secondary College, Brisbane.

She began her working life at Basil Stafford Training Centre, Wacol supporting people to leave the institution for community living during the 1980's & 90's. Her interest in supporting people to live rich and inclusive lives led her to complete studies in Social Services. As a support worker she worked with the one family for 25 years and continues to be involved in their daughter's life both as a friend and a circle member.

Supporting an experience of Inclusion

Growing up in the tail end of the "baby boomer" era, people with physical disability were not part of my world. I have no memory of meeting a person with "obvious" disability until late in my teenage years where I recall standing in a shopping centre, transfixed by a woman in a wheelchair. The following year whilst on a school excursion to a residential institution in Chelmer, Brisbane, I was internally traumatised to know that such a place existed, where the children seemed hidden almost.

In 1980 I joined Intellectual Disabilities Services at Basil Stafford Training Centre, at Wacol, becoming a Residential Care Assistant. I can still recall vividly how shocked I felt for the people who were alienated and lived within the culture of their institutionalisation. When a position became available to support five men to leave the facility to live in the community I was keen as mustard to work with them. It was 1982 and deinstitutionalisation was to become the mantra, combined with the guidance of Wolf Wolfensberger's "normalisation" goals that defined Queensland government policy practice. They were heady days as the community became "socialised" to the people who had spent their lives locked away – and vice versa. The very fact that socialisation programs were required for those who had been isolated from others demonstrated to me some of the impacts of growing up in a life that is segregated.

Many moons later as a mother with two children who attended a local state school, a young boy called Luke happened to join the school. I came to learn that he was in Grade Five, and my children knew his two younger brothers who were also students there and up until then Luke had been attending the special school located next door. Whilst it seemed Luke had just arrived to begin in his class that year, I came to learn over time just what careful planning was required to help this new member to join the school. Luke's parents had worked closely with the Principal to provide Luke the opportunity to attend the same school as his brothers. With the P&C, the Principal facilitated the practical changes needed for the school to accommodate a person in a wheelchair, such as installing a lift and building an accessible toilet block.

The school community was welcoming of Luke and the staff collaborated to make sure Luke could obtain growth from his education experience. Some selected staff at his old school worked together with the teachers to design the individual support Luke needed during the school day and he had a teacher aide to support him in his classes. In liaison with Luke's parents, the Advisory Visiting Teacher (physical impairment) from Education Queensland designed a simple communication book that enabled Luke to have a say in what he may want or need by the raising of his hand or head. A "switch" device was also incorporated as a communication tool where messages or events could be recorded and shared, allowing Luke to offer some of his insights and experiences.

We saw great changes as Luke grew much more involved and engaged with his peers and it was clear he was enjoying his new school. That was the year I discovered Luke had a neck! When he first came to school his chin sat into his chest, and as the year progressed we all witnessed his face raise up and look out to the world.

After Luke had attended two years at our primary school I was approached to become Luke's second teacher aide for his Grade 7 class in 2011 and for the last six years I have continued to support Luke. During this time he moved onto his local catchment high school. It is a very welcoming school which takes its motto "I am safe, I am responsible & I am respectful" very seriously.

After five years Luke remains the only student who uses a wheelchair at his school. Luke's curriculum includes individualised goals that focus on communication and socialisation. We were fortunate that when Luke started at his high school his teachers were open to include him. This demonstrated to others in the school community that Luke was someone worthy of relating to and it laid a strong foundation for him to be seen as just another student alongside his peers.

A large part of my work is creating opportunities for people to get to know Luke. At first, some of his peers needed to be asked to push Luke in his chair if going to the same class, while others initiated seeing the need to wipe his face or walked with him between classes and anticipated any help he would need to get there. A few would just sit down outside the canteen with him and feel okay about talking to Luke with little feedback from Luke himself. Over these past five years at high school Luke has made a small but close group of friends and interestingly most of them have become the leaders of the school.

Many students see my role as Luke's convener and tell me what Luke needs from me to support him. This can make it difficult to facilitate natural friendships forming as the students mostly feel they need to go through me to engage with Luke. For example, if Luke raised his hand many students would tell me he had something to say as if it was to me that Luke wished to speak. We do try to encourage his peers to use his book without me being involved and we model this constantly to the point one student could recite Luke's original communication book by rote to us. While many students appear to lack the initiative to engage with Luke, he is a familiar face at school now and this is influential in shaping inclusion and respect into the future.

Whilst I do withdraw to allow "their time" often the school schedule, bells, routines, etc. means I can never go far from them. I'm still trying to work out how to gastro feed someone and pretend you aren't in their space?

One thing I do is capture moments when something noteworthy happens. This can be ordinary things such as when a student pushes Luke, or sits with him at the swimming carnival through to deeper connections such as Luke being moved by the music they played. I try to take a photo and later make a copy for the people involved and also for Luke's family. While I try to blend in to help bridge communication, I am very aware I am still an adult with power so I aim to be casual, friendly, relaxed, sensitive and interested if any of his friends are around. I always keep an eye out for opportunities to encourage friendship with Luke.

Throughout his schooling Luke's interest and participation within music immersion has been the stand out feature, and his pure joy to be "in-the-music" is plain for everyone to see. Some music students have commented that they look out for Luke's response whilst performing to know if they are doing it right or not. Once a week for seven months last year Luke attended rehearsals, eventuating in three performances with his school in the musical showcase "Popstars", a tribute to 90s music. Luke absolutely beamed throughout this. Many students had to get involved and move him on and off stage, up and down lifts, and change his outfit. It was a brilliant exercise for inclusion to occur, and a few of the cast and crew have befriended him since.

> ***Whilst it seemed Luke had just arrived to begin in his class that year, I came to learn over time just what careful planning was required to help this new member to join the school.***

As a teacher's aide it has become clear to me that the whole school community can be a part of making sure Luke can enjoy life as a student. For example, not only are the the school's Principal and Business Services Manager welcoming of Luke, but they also oversaw the repair of the lift onto the stage of the school hall and auditorium so Luke could participate in the year's musical and his formal ceremonies. The school cleaners always have made time to greet and chat with Luke. It's these little moments of exchange that hold great depth and are so important.

There is much required to allow a successful "inclusive" life, and it can be compromised constantly. Whether it be communication technology breaking down, health concerns or just the time it takes to perform certain tasks, these occurrences can separate Luke from socialising and being a more active student. There is no point in waiting for a perfect time to truly "include" Luke in his school. I am so grateful to be part of this opportunity for Luke to become a part of ordinary school life. Luke has much to teach us about the importance and the fragility of inclusion.

I assume that Luke is competent to understand this, regardless of the little feedback he may be able to give. Luke engenders an attitude in us all of tolerance, humility and acceptance of the spectrum of our human conditions. These are subtle "lessons" that resonate for years.