

CRUCIAL TIMES

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Editorial

The Sustainability of Good Ideas

Jane Sherwin

To borrow a phrase from elsewhere: what we need are good ideas and good people; the rest is just money.

The distinction between viability (which is largely about financial security) and sustainability expands our realisation that not only is decent infrastructure funding important, but even more important is, that as a community and as a sector, we need to sustain ideas and practices that will ultimately lead to better lifestyles for people with disabilities and better communities.

This issue of CRUCial Times explores the notion of sustainability, and in particular, the sustainability of good ideas, people, spirit, leadership, and vision and challenges the viewpoint of money as the only long-term salvation.

Good ideas that have long been sustained in Queensland, since at least the 1960s, include that people with disabilities belong with families in local neighbourhoods, growing up to have ordinary lifestyles like other people. These good ideas are at the heart of the community living movement.

Despite a recent national resurgence in efforts to congregate people with disabilities and separate them from the real world, CRU and others are committed to good ideas that foster community living.

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CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

In these times, there are things that we can all do to keep the flame of good ideas alive and fan this spark in the people and in the work.

- i. Know that these ideas will be seen as counter-cultural. There have long been ideas and efforts that lead to people with disabilities being with 'their own kind', living in a parallel world to the real world. In fact these ideas have been dominant throughout history and across cultures. So therefore it has been and probably always will be hard for the ideas about ordinary lives in ordinary communities to find fertile ground. Don't be surprised when talking about and working towards children going to regular schools, people living in their own homes not facilities, working in real jobs, and having the authority to solve their own problems is responded to with glazed eyes, furrowed brows and frustrated responses at times. If we expect such responses then we can feel less surprised and dismayed by them.
- ii. Join with like-minded others, and be confident that there are family members, people with disabilities, service and government workers who daily enact their commitment to communities and systems that embrace better lifestyles in the real world as opposed to a service world. These collegial relationships remind us all that these ideas are not just the ideas of a disenfranchised few, but rather are shared by many across the world.
- iii. Find examples of these good ideas in practice, read, talk and write about these. In every town across Queensland you will find there will be examples of people who are having a regular, typical life; not only present and participating in community life, but belonging and contributing to the community in which they live.
- iv. Find good theory that supports good practice. Support the application of the idea with explicit assumptions and coherence between the vision and how it is achieved.
- v. Develop the resilience of the people with the ideas. Provide nurturing opportunities that enable people to commit to this movement for the long-term, and provide opportunities that challenge and extend people's ideas.

- vi. Get better at describing and explaining the good ideas well. This is quite a challenge as the language of the community living movement has been co-opted and perverted, such that community living has been misinterpreted to mean simply presence in the community or being served by a community agency. We need to find ways of articulating both what community living is, as well as what it is not. We consciously use phrases like 'typical lives', 'rich and meaningful lives', 'belonging' and 'social inclusion', and we must continue to find language that evokes notions of the common humanity of us all and visions of better lives.
- vii. Above all else, what will sustain this movement is the commitment to understand each person with a disability as a fellow human being, to have a dream of a good life for this person as one would for anyone else. This also requires us to perceive and understand someone with a disability beyond the role of 'disabled', and to see the other wonderful human roles that the person has or could have. This is beyond human service ideology. This confronts us on a daily basis about our capacity to relate to someone who has a difference that is often judged harshly in our society.

We are in a time when progress is slow, and when it appears that these ideas are not shared by funders and policy makers, or by other community members. It is confusing for Governments and bureaucracies when the loudest voices call not for a vision of a better future, but for investment in retro-vision: institutions, villages, group homes. It is distressing for those with good ideas to see these things funded and supported by policy, in the absence of support for progressive ideas.

Sustaining the good ideas is not only a demonstration of commitment; it is also a form of resistance. The good ideas recognise that people with disabilities feel exclusion deeply and share the same aspirations for decent lifestyles as all people do. The good ideas are based on values that are consistent with social justice, diversity, rights, community capacity building, citizenship, people solving their own problems, and cultural values. We know that what has sustained these ideas in the past will sustain them into the future: will, creativity, compassion, insight, practicing resilience, joining with others and the enactment of ethical leadership.

From the President

Mike Duggan

In these times, sustaining ourselves both as individuals and as part of society requires us to keep on 'peeling an onion' – stripping away at the issues and concepts that have influence over the lives of people with a disability, their families and the wider community and attempting to understand the message behind what we discover. We cannot afford to be content just to accept the superficial veneer of life; life must have a meaning, if it is ever to become worthwhile and meaningful. Thus, we must constantly delve into ourselves to discover the fundamental values that we so dearly hold on to, consciously or unconsciously. These are the beliefs and fundamental values that inform our attitudes towards our work practices and toward people generally, but of course particularly those with a disability.

We have to show leadership in raising meaningful worthwhile dialogue around actively promoting positive values in regard to people with disabilities. When we maintain or even raise the level of discourse around values, and attempt to focus greater attention on values engagement, we contribute actively to how people who are the most vulnerable now and in the future will lead their lives within society.

The prevailing milieu for many people with a disability, their families and allies and community organisations is one that presents many challenges, some of which are major changes in funding arrangements, uncertainty within the political sphere, and the extent of unmet needs. When we live in a values vacuum, the significance of these challenges is not only heightened but can be more systematically damaging for those of us who have been labelled as having a disability. The more sophisticated society becomes, the more under threat the very lives of people who have disabilities become. We definitely need to take more of a leadership role in this precarious situation and we need to promote, nourish, nurture and sustain leadership wherever we see it.

I believe that when individuals embrace some of the current challenges to sustainability with a feeling of energy and a clear sense of direction and have strong commitments to that which they are passionate about, then, this can be both inspirational and grounding at the same time.

We can be sustained by the realisation that there may not be any right answers, or indeed, any easy answers at the moment. We can be guided by our history while constantly searching for new strategies and fresh perspectives which might spark fresh enthusiasm and a sense of hope and help us to retain our viability.

Above all, we must be guided by an unwavering commitment to our values and our mission by continuing to be clear and vigilant about our commitment to the positive value of people with disabilities and their needs for a decent life in the community. This means keeping people with disabilities and families at the centre of our work, seeking ways to make it possible for the grassroots and leadership of the community sector to be visible, focused, united and influential, and continuing to inform and encourage people who are working to protect and promote the interests of people with disabilities.

And in all of this it is important to remember to look after ourselves. Let us not forget the value of a well-earned rest; a time 'to pick the flowers' and to nourish and invigorate the soul is one of the many ways we retain some sense of self in the midst of difficult times. A very good friend said recently that we should be able to experience joy in our lives. I really think this is so true.

PEACE!

Mike Duggan

A SUSTAINABLE COMMUNITY FOR MY SON

*In this contribution **Sally Richards** describes the key elements of the family-governed structure which she and two other families set up to support their sons to live a good life in the community. Sally believes that no single person in a family is more important than any other. Hence her struggle has been and continues to be not only for her third son, Jackson, who has a profound intellectual disability, but for herself, her husband and her other three sons. She is a teacher, writer and advocate and represents families on various government and non-government reference groups and has presented at conferences, workshops and forums*

My twenty-year-old son, Jackson, is a young man with the potential for a great future. He is a thrill seeker, a music lover and a car enthusiast; he has enormous stamina and perseverance, rides pillion on a 750cc BMW motorbike and enjoys bush walking and boiling a billy. Everyone who really knows him loves him. He also happens to have very high support needs; he needs one-on-one supervision and assistance all his waking hours. Without caring people with vision to support him to lead a good life, the typical future he can look forward to is one diminished in real and valuable roles and adventures.

He has so much to offer. However, we live in a society that often refuses to acknowledge the contribution he can make; a society which does not, to any large extent, value or respect people like Jackson. He is seen as 'other', a lesser kind of human who can contribute little and is not entitled to the support he needs for his life to be rich in people and experiences.

As Robert Theobald says in Anne Deveson's book *Resilience* (2003):

Increasingly it seems to me that we need to rebuild at much smaller levels of neighbourhood, and develop the kind of face-to-face interactions where groups

are small enough to make connections at very personal levels. It's that old adage: 'It takes a village to raise a child' – and we've lost our villages. We need to allow people to talk through a growing feeling that society needs to be more compassionate, and to take better care of the children we bring into the world.

Jackson needs to be part of a community that will grow around him and with him as he matures. However, unless we do some structural work on his community, he risks living always on the edge of life. His community needs assistance, encouragement and support to include him fairly and squarely in its midst. To provide these vital incentives, I have developed, over the past five years, four supporting structures which are interconnected. Each of the four structures: family governance, planning, a circle of support and a small business is vital to the overall sustainability of Jackson's place in his community.

The initial impetus came from a Community Resource Unit conference several years ago where I heard Michael Kendrick speak about family governance and where I established a friendship with two other mothers who were also from Canberra. We had not been friends before but realised very quickly that we were like-minded and that we held the same values about the importance of our sons having a real, not a token life. We were three women who could use a common vehicle, family governance, to reach individual solutions for our families. So, in 2005 I invited them to join with me in establishing a family-governed project which we called *Getting a Life*.

Getting a Life provides the first building block of Jackson's community. He and the other two young men are at the centre of the project. The families and the coordinator form a circle around them; a hosting agency, which is philosophically aligned with the group and understands its very important but back-seat role, is to one side; and a funding body sits underneath.

As a family-governed group we, the families, have the autonomy to make decisions about the people we serve (our sons), the emotional support of the other families, the practical support of our coordinator, the guidance of the hosting agency, and the financial support of the funding body. These elements of the project are

interdependent and each sustains and supports the others.

The second ingredient of Jackson's community is a broad life plan. Jackson's plan evolved some years ago but I have used PATH (Planning Alternative Tomorrows with Hope) to record it. PATH is a highly visual, person-centred planning tool which, with the assistance of a facilitator and grapher (drawer), uses very simple drawings and words to represent a person's goals and the eight steps leading there. The result is a colourful, visually attractive record of the person's hopes and potential achievements at some time in the future – this could be anywhere from twelve months to five or ten years hence.

It is important to articulate goals as this encourages and assists us to think about the kind of life Jackson wants, the steps and stages necessary to achieve that life, what's blocking him from having that life and who and what can assist us to realise his dreams. The PATH is flexible and changes often. It represents his life at any one point and needs to adapt as his circumstances, achievements, needs and goals change.

The third sustaining element of Jackson's overall life plan is his circle of support. It is also the most difficult part of the whole equation. Many people struggle with circles and so do I. Circles can be relatively straightforward to establish but are notoriously difficult to sustain.

A circle of support must be made up of individuals who have the common goal of wanting to make a real difference in the life of the person the circle supports. I have invited a variety of people in the past. At different times my own friends, family members, Jackson's support workers and other interested people have all been involved. We talk about Jackson, what is happening in his life, what is good about that, what is not so good and how we can make it better. It is a fun, interesting, brain-storming

event which always has food, laughter and, often, champagne.

The most recent development in the creation of Jackson's community is the establishment of a small business. This is a PO Box mail pick-up and delivery business and it is still in its fledgling days. Jackson's support worker will also be the driver of the van. The aim of the business is to give Jackson a valued role and meaningful employment doing something he enjoys. It will also give him the opportunity to meet many small business owners and for them to know him. I believe that he will form relationships and friendships as a result of being a paid employee doing a real job in the real business world.

In creating all of this, I have discovered something rather amazing. When people see a person striving to create something and when they see commitment, energy and determination, many are drawn in and want to be part of the creation. If they are invited to be part of Jackson's community they are likely to accept and, once there, to stay – at least for a while. This is not a result I would ever have anticipated but it is a powerful force which helps to sustain my energy and which helps to sustain Jack's life plan.

So creating and sustaining Jackson's community is a many-layered and many-faceted enterprise. Some parts, like family governance and his business, are comprised of many smaller pieces which all join to make up the whole – much like a jigsaw puzzle. These in themselves, along with the circle of support and the PATH, are sections of the bigger picture: Jackson's sustainable community.

It is not easy – but then life wasn't meant to be, as a former Australian Prime Minister once said. However, it is exciting and rewarding and offers the potential of a real, interesting and valued life for Jackson supported by the community we have created for him.

A circle of support must be made up of individuals who have the common goal of wanting to make a real difference in the life of the person the circle supports

THE ROLE OF LOVE IN A SUSTAINABLE WORLD

*In this piece, **Erik Leipoldt PhD** considers the pivotal role of love in shaping a sustainable, interdependent life. Erik has a varied background and has lived with quadriplegia since 1978. He is involved in a Citizen Advocacy program; is an Adjunct Researcher with Edith Cowan University and is a senior tribunal member in the Western Australian guardianship jurisdiction. He has developed a website on alternate energy sources to explore the contribution that might be made through a disability perspective of interdependence towards a sustainable world.*

Every day the news has stories of global warming and climate change. We could say that we are now living in an environmentally-disabled world. Natural cycles have been disrupted, causing floods, droughts and rising sea levels, and making many people highly vulnerable to their effects. We can link the effects of global warming back to the thinking which developed during the Age of Enlightenment, over five hundred years ago, when ideas about individualism and materialism gained acceptance; ideas which were later fuelled by the mechanics of technology and cheap fossil fuels. We find similar attitudes and ideas playing a role in the disablement of people, except that disability is less newsworthy.

Often for both our disabled environment and people who live with a disability, the immediate remedy is typically seen as more money and the wonders of technological fixes rather than attempting to change individual values or societal attitudes. Thus, in the climate change debate, the immediate remedy involves huge investments in alternative energies and infrastructure, while in the area of disability, the remedy is often sought through the provision of more money for services, through medical cures such as stem-cell technology, and through additional laws about rights.

These approaches are based on old thinking which over-emphasises the individual, the material, a strong sense of control over life, and

the right to exercise that control as we see fit. Living within limits is not in this ideology's vocabulary, nor are dependency on others, frailty, losses of individual control, and vulnerability. These are all inevitable parts of any person's life at some point, whether newborn, ill or frail-aged.

Old thinking is part of the problem because it devalues these realities of life and the people that embody them. In today's society people are primarily valued according to their contribution to the economy hence, there are negative social attitudes towards people with disabilities who are patently vulnerable and often poor. So therefore, as a person with a disability, never look for salvation as a 'consumer', as part of an economy that depends on an idea of everlasting material growth. This ideology by definition can never fully value you – at most you will be an 'honorary consumer' in an economy, not a person in a community.

Merely living as 'Homo economicus' has brought its social problems too, such as losses of public trust, high rates of depression in developed countries, loneliness and social disconnection. So it's not exactly a sustainable way of doing things.

Astonishingly enough, to old thinkers, the experience of disability actually contains some very practical lessons for living life sustainably. A sustainable life involves the wisdom of knowing when to accept limits and which to cross. So, acceptance of your impairment may be helpful but acceptance of negative attitudes towards them is not. It involves learning the skill of using limited energy responsibly in order to make it last. In using a wheelchair as I do for instance, it is second nature for me to try to get the most out of every situation and not to waste my rather limited energy. Living sustainably means living life as-it-is: interdependent, with temporarily-felt independence and dependence. Reaching out for relationship with others and our environments is our key 'thrival' skill. It allows us to live so much more fully than just to survive – usually reserved for the 'fittest' competitors anyway. I consciously try to build relationships with others around me as I know from experience that this is the highway towards having a good life and to feeling good.

Human wellbeing and happiness primarily depend on being loved. This involves positive relationships and the mutuality of giving and receiving love to the extent each can. Being

loved involves being supported to express one's potential and being protected in hard times. We need that kind of thinking and acting to adapt to living well within a disabled world as much as in living well with disability.

The value of this relational living, with its sense of inner growth and meaning, is actually well-known to most of us: but it can be just so easy to forget about it under the daily torrent of consumerist messages – especially when you try to live as if you are independent and self-sufficient, something none of us ever really are.

Many studies show that people with disabilities, including those who require extensive assistance and support, report their lives to be as good as, or even better than, average. This understanding of what is a good life rests on relational rather than individualistic values, on interdependence and acceptance rather than independence and control. Such understanding can transform the lives of many people, who are facing significant and life-defining moments such as aged people and even people close to death. When my mother was given the definite prognosis that her cancer was terminal the first thing she said to my sister was: "Well, in any case we don't have to talk about that anymore then." So, instead of running around for, likely elusive, cures, her acceptance meant that her remaining months were filled with the warmth of relationship. In that way she demonstrated the meaning of sustainable life – being supported in her suffering while giving much of great value. I think that is exactly what Carl Jung meant when he once said that the fundamental causes of suffering cannot be fixed, but only transcended. In our world of so many daily and often trivial choices, my mother chose to accept what-was. I am very proud of her.

A sustainable world requires the sort of thinking and values that my mother lived, that many people with disabilities, and others live. There is much talk about 'renewable energy sources' in dealing with climate change. But if merely guided by old thinking we will not achieve a sustainable world. Love is the only truly renewable energy source and the essential basis for a sustainable world. Such a world is not possible without engaging with dependence and vulnerability. A full and rewarding human life – as must a truly sustainable world – includes those who are most vulnerable.

Achieving a sustainable world depends firstly on personal practice. As we increasingly feel the

world's disablement, perhaps humanity will start to reach out for such relational policies and practices. A Utopian dream? No, I think this would merely be a down-to-earth attempt to accept life as it is, rather than continue to live the disabling myth of material individual independence. For the past five hundred years, the consumerist policies of material individualism have shaped much of our lives, perhaps relational policies could shape our future. Now is a good time. By all indications we have much less than five hundred years to do that.

Living sustainably means
living life as-it-is:
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temporarily-felt
independence and
dependence

Some Reasons Why Spending More Money Does Not Inexorably Improve Service Quality And Sustainability

Michael Kendrick consults, writes and is active on matters of quality, values and leadership in many countries. He has a passionate interest in the provision of quality services to people with disabilities. Michael, who is Canadian but now lives in the USA, has been a regular visitor to Queensland over many years. With over 25 years of experience, he is well known for his work on Leadership, Quality, Advocacy, Safeguards and the promotion of community living for people with disabilities.

We exist at a time in our culture's history where we have invested striking amounts of money into human service systems in all aspects of our lives from early education through to old age. These systems have resulted in the creation of multitudes of specific human services, as well as a wide range of bureaucracies, both public and private, to manage them. In many bureaucratic cultures, money is often posed as being something akin to the essential lifeblood of these human services and systems and the guarantor of service quality and sustainability.

This conviction arises from a distinct view that money is the active and fundamental enabling agent of good human service outcomes, at least in comparison to other possible drivers. It is not normally the case that this claim is actually embedded in empiricism, as this conviction owes more to ideology than to demonstrable studies that uphold this conclusion. This overstating of the role of money becomes more obvious when the issue is examined more

closely, particularly in relation to the role of suitably-talented people in guiding how money is spent.

It might well be that if money were spent in a different way, then some benefits could be expected. However, if what is being provided is inherently flawed, then investing more money into what is already inadequate will simply make that shortcoming a more expensive one. Money – even in abundant supply – can neither overcome flawed practice nor guarantee good sound practice. Good practice, rather than simply spending more money, is a crucial and active ingredient in helping people to obtain better lives.

In addition money rarely motivates people to do the right thing. The suggestion that people will become more virtuous, if they are induced to do so with the offer of additional money, is inconsistent with what can be routinely seen in everyday instances in both life and formal human services. The commitment to seeking out and doing the right thing towards others arises not from payment, but rather from the values and ethics of the individual and the organisations involved. If this were not so, then any individual's motivations and commitments could simply be purchased. Conceivably, the higher the price offered, the more virtuous the candidate.

The way money is spent is
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use

Increasing money payments to people does not equate with acquiring good character, because good character cannot be bought. Clearly, many people would be deeply offended at the suggestion that the only reason they do the right thing is that someone is paying them to do it. Similarly, paying someone more will not invariably result in a proportionate increase in virtuous conduct. In fact, many people will point out how corrupting money can be for those people whose values and ethics are already weak. Equally, many of the most motivated and accomplished of individuals and organisations have achieved their excellence using what are essentially normative budgets. In fact, impressive quality on a sustained basis may be present in any number of comparatively poorly-funded but otherwise effective human services.

The capacities of people play an fundamental role in improving service quality and ensuring long-term beneficial outcomes for people who use human services. If people lack crucial and needed capacities, adding more people, or paying people more money, will not overcome this deficit; simply spending more money on people, who cannot perform, is simply a way to squander money rather than to gain a benefit. The hoped-for results can only come from suitably-equipped people, so relying on people who are not achieving results will predictably disappoint. Money does not solve problems; people do. If people cannot do this effectively on behalf of the people they support, then no amount of money will change this. Thus, the emphasis should be on equipping people to do better and to make money available in support of this. By offering options to positively develop the capacities of people, the quality and sustainability of their efforts will most certainly be strengthened.

It is a fundamental axiom that the crucial question is whether one is spending money on the right things, not whether one is simply spending money. The way money is spent is only as good as the wisdom of those who authorise its use. If the spender is incompetent, cannot distinguish quality and value and is easily seduced by quick fixes and sham, then the old phrase that 'a fool and his money shall soon be parted' is quite apt. On the other hand, if the spender is wise in terms of seeing what people really need in their lives and is proficient in obtaining these, then one might have more realistic expectations of beneficial outcomes. It all revolves around the care and attention that is given to defining what are the 'right things'. Money alone cannot do this. However, money in the hands of judicious and competent people can bear fruit. It is important to see that this distinction is a profound one.

There are times when money may actually complicate rather than advance matters. Adding money indiscriminately to a given situation may bring various kinds of unhelpful pressures and distractions as opposed to somehow being a benign influence. For instance, additional funding money has to be managed. When money and its speedy management get people's best energies, then it is quite possible that attention could be drawn away from the valid centrality on the people who are being served. In this regard, money ought not to be thought of as always being beneficial, because the spending of money may mean pressures for a rush to action and decision. It may also give rise to

many other agendas that could serve to compete with a 'people-first' agenda.

Money, therefore, has to be viewed simply as a resource rather than a panacea. Money is an inanimate resource and has no vitality or moral meaning in its own right. These elements are only brought into force through the qualities of the people that mobilise the available money. If these qualities are lacking, then money in itself cannot overcome this shortcoming. To imbue money with powers that rightfully belong to people is to render it an implausible panacea. However, in the hands of the right people money can be a great force for good.

Sustaining The Vital Essence of A Family-Governed Service

Elsie Butler is a founding member of a small family-governed service which provides support to people with a disability in Far North Queensland and currently she holds an executive position on the management committee. In this article Elsie describes the challenges in maintaining the original passion which drives people like herself and in finding ways to encourage and inspire future generations to continue along this path.

Some years ago, I was one of a small group of like-minded people who shared a dream for our family members with a disability: we wanted their lives to look similar to those of their siblings and others in society and we decided to start a service to provide support services to our family members with a disability. The philosophy, vision and values of the service was underpinned by our belief that people with a disability could be assisted to have opportunities, to make choices and to have a say in their daily lives, to have a place which was their home and to be involved in and part of the community through activities of life, work and play. This family-driven service which understood the value and importance of the involvement of the family, would always take into account what the impact on the lives of the people using the service would be when making decisions. Our service and many similar

services were started by families who saw there was a need for an alternative, individualised approach to service provision which was dominated by large service providers whose services are based around congregation and segregation.

This perspective and history surrounding small family-governed services is in danger of becoming lost in the current disability climate. 'Big is better' seems to be the prevailing trend and pressure is being exerted on small services to consider expansion or amalgamation in order to fit the current thinking which is that a bigger service will make the most of limited funding. This thinking largely looks at the issue of funding as one in which economies of scale are considered more relevant than service quality and ignores the reality that small service providers are able to provide individualised and personalised support services to a small number of people, who are well-known to the service while large service providers often adopt a 'one size fits all' approach.

In addition, current trends seem to indicate that there is some scepticism that many small services will survive beyond their founding members. This seems to indicate a lack of commitment to supporting small services to continue to provide an alternative to the congregated and group home model. Yet small services have demonstrated their flexibility and capability to not only provide an alternative but to provide people with a typical lifestyle in community with options which would otherwise not be available to them. The value of having a personalised service where the people using the service are known and valued for their gifts and talents and as members of society by those managing and directing the service is the essence of the uniqueness of these small services. It requires deliberate thinking and acting to keep the person as part of and connected to family, friends, neighbours and those who one comes into contact with in the journey through life and its daily activities.

Sustaining service delivery and the future viability of small community-based services is at the heart of all of those who have been involved in the founding and ongoing management of such family-governed services. The vision of the founding members for their sons and daughters to have a life similar to others in our community and to be involved in and part of the community through ordinary activities of life, work and play

are the very reasons for the existence of the service and for the continuing perseverance of those involved in service governance. We believe our service has demonstrated that people can be supported to become more independent, grow in self-esteem and undertake their daily activities like everyone else, including people with little or no funding, who depend heavily on family and informal arrangements.

As parents grow older, many small family-governed services are facing additional issues of planning and responding to the potential for an increasing level of demand for support services. Planning for the future and the needs of a person when parents are reducing their involvement stretches the capacity of all concerned. Developing additional support responses, particularly informal connections involves a considerable amount of creative thinking, planning and support for fledgling beginnings to reach possible fruition. In addition all services are faced with the complexity of ever-increasing requirements from government to demonstrate funding accountability and responding to legislative requirements and regulations.

While small services are busy responding to these external and internal influences, they can easily lose sight of the original vision of the service to provide people with a good life. People's lives are a world apart from all the accountability. What they want is for the service to support them to have real lives, relationships and to be part of their community. Real lives mean having opportunity for self-expression and to have meaningful activities and occupation which allow the normal ebb and flow of life.

Small family-driven services which keep this vision of a good life for people with a disability in community need to constantly be on the look out for new people to replace founding members. We regularly scan our networks of family, friends and others to find those who show an interest and an understanding of the vision and values of our service and who might step forward and take an active role in the future. In this search it is important to identify the people who can be fostered into leadership positions and encourage them to take on or continue their association with the service. People are more likely to develop a long-term commitment when they feel a sense of belonging to the organisation and that their contribution is valued.

Those of us who have been associated with and travelled the road with people and families to realise dreams and aspirations, share in their sense of progress, fulfilment and achievement. This inspires us to be attentive to and maintain the vision and values which allow ordinary and typical lives for people using our service.

Sustainability And Spirituality

*In this article, **Dr Noel Preston AM** brings a spiritual perspective to questions of both personal and global sustainability. Noel is currently adjunct Professor in Applied Ethics at Griffith University and is also a Minister in Association at the West End Uniting Church in Brisbane. As an academic he has held senior positions at Griffith University and QUT and has been involved in many social justice organisations and campaigns. Before his retirement in 2004 he was the Founding Director of the Queensland Centre for Social Justice. He has written several books, including *Understanding Ethics and Beyond the Boundary: a memoir exploring ethics, politics and spirituality.**

Questions of 'sustainability and spirituality' arise for us all at some point in our lives, especially at those difficult times in life when events confront us with the questions: How do I keep going? Why should I keep going anyway? The great moral exemplars of history like Mahatma Gandhi, Nelson Mandela and Aung Sun Su Kyi testify that their struggle to sustain moral courage and faithful witness in difficult times is essentially a spiritual journey; we see a similar phenomenon in the lives of countless unknown persons who overcome seemingly overwhelming odds by drawing on inner resources of the spirit. But what do we mean by the terms 'sustainability' and 'spirituality'; terms which are widely used these days?

The term 'sustainability' has become part of the lexicon in the fields of economics and politics as concerns about the natural environment are increasingly at the centre of policy, commerce and lifestyle. The debate about global sustainable development in the face of escalating harmful impacts caused mainly by

human beings is the core challenge of the twenty-first century. In this context, sustainability means 'meeting the needs of the present without compromising the ability of future generations to meet their needs'. In related contexts, such as empowering people with disabilities, sustainability is essential to safeguarding the future of all who are vulnerable.

From this starting point, sustainability may be explored as a principle for living a life true to its nature and possibilities. In this sense, sustainability is almost a synonym for 'viability' or 'resilience' and also 'integrity' or even 'well-being'. Indeed, sustainability rests on an understanding of life itself which, in turn, suggests that individual life forms, species and eco-systems depend on a web of interconnections. Not only do all living things breathe the same air, we are composed of very similar genetic structures. Indeed it is a principle of life that the parts are only viable if they are integrated with the whole. None of us – however

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endowed – can live without others, human and non-human. Cut off from connections with others we are all disabled and our lives unsustainable, even though it is also in our nature to cherish individuality and find strength in solitude.

There is surely something magnificent and mysterious, even sacred, about the nature of life. Consequently it is not surprising that ecologists like David Suzuki talk openly about eco-spirituality. The suggestion is that sustainability requires an attitude or standpoint informed by a spiritual perspective, one that challenges a philosophy of exploitation.

What becomes evident from this standpoint is that an authentic spirituality is not only required in the big picture for life on earth but also for sustaining each individual life.

'Spirituality' is a term that defies easy definition, while to some it is a term that is alien. It is

certainly not to be simply equated with religion or religious beliefs. Spirituality is cultivated in what is sometimes called the 'inner life'. To me, spirituality refers to the human quest to live life with a meaning and purpose that is linked to a consciousness that we are part of a reality beyond ourselves. Therefore, one's spirituality helps shape answers to questions which are fundamental to our existence, questions of identity and community.

As I look back across times when I doubted my own life's sustainability, the sustaining strength which enabled me to move on from crisis is rooted in spirituality. For instance, the shadow of cancer has surrounded me for sixteen years; through these years of difficulty I have often recalled the words of one doctor who sought to practice medicine holistically. He reminded me that 'wholeness' derives from the old English word 'hal' which also gives us the term 'healing' as well as 'holiness'. In other words the journey to healing, wholeness and holiness is made on the one path. In this context holiness is not some state of perfection, set apart from ordinary life, but a perspective for engagement with a sense that all life is sacred, to be celebrated and respected.

Along the way I have learnt that maintaining a sustainable, purposeful life – and this applies to a community or an organisation as well – requires us to confront boundaries while also accepting limitations. A balanced life is therefore derived from a sense of sustainability integrated with an appropriate spirituality. At its heart, sustainability linked to spirituality is expressed and experienced as love in its many forms – from compassion, physical intimacy through to social justice. Similarly, so understood, sustainability is fundamental to the task of supporting otherwise marginalised people within the community.

It is suggested that love makes the world go round. Certainly love and the life-giving spirit are intimately connected. Indeed love is grounded in the interconnectedness of all life and our mutual belonging as a species and across species. Love is the fundamental passion which generates and nurtures life and the core of our human capacities and needs. Loving is both the cause and cure of much of our pain. In the end it

inspires hope, a necessary ingredient of sustainability.

In his masterly essay, *The Art of Loving*, Erich Fromm expands the idea of love beyond the interpersonal. He concludes: "Love is not primarily a relationship to a specific person; it is an attitude, an orientation of character which determines the relatedness of a person to the world as a whole, not toward one object of love...If I truly love all persons, I love the world, I love life".

Cultivating that attitude, that orientation of character – which is at the heart of an authentic practice of spirituality – is basic to promoting sustainability at all levels, personal and global.

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