

Kendrick, Michael J., "What Remains Worth Struggling For", Chapter 12 in Relationships and Everyday Lives: People With A Disability and Vital Communities, CRU Publications, Brisbane, Australia (2003)

## **Chapter 12**

### **What Remains Worth Struggling For**

**Michael Kendrick**

*Michael Kendrick has a passionate interest in the provision of quality services to people with disabilities. Michael, a Canadian who now lives in the USA, has been a regular visitor to Queensland over the past fifteen years. With over thirty years of experience, he has made a very significant contribution to the field as an educator, consultant, and advocate. He is well known for his work on Leadership, Quality, Advocacy, Safeguards and the promotion of community living for people with disabilities. In this chapter, which discusses the nature and inevitability of struggle, Michael reminds us that the inner struggles are the most defining ones, even when we are dealing with the outer struggles of activism, advocacy and collective social movements.*

#### **The Inevitability Of Struggle**

There is a wish in all of us that life be not so taxing and difficult. We resist the idea of making something as seemingly dire, as struggle often is, to be anything but an exception to the norm. The thought that life could be equated with struggle is abhorrent to our modern belief that suffering of all kinds ought to be entirely escapable. Perhaps we no longer appreciate that our ancestors would be utterly puzzled by the idea of the world being a site for perfect happiness. Curiously, many of them would have said after some reflection, that they actually became happier when they came to accept the struggles of life rather than to run from them. We are pulled in many directions by the prospects of struggle, and finding how to manage it will rest, to a great extent, upon what we believe about the inevitability of struggle.

If, for instance, we believe that struggle is harmful to us, then it is quite logical to avoid it, and to disparage taking up any challenge that might result in strife, tribulation or frustration. Yet if this belief were to be pursued with any consistency, only easy problems would ever be faced, and the admirable strengths that arise at times of great human struggle might well be lost from sight. There would be no incentive to exercise courage, to seek or inspire idealism, to show solidarity with other people, or to commit acts of great virtue. We would lack edifying role models, and most certainly would be deprived of the excitement and spiritual uplift that comes from witnessing the good that people can do when it is important enough.

At the same time, not all versions of struggle are ennobling, and it is important not to lose sight of the many ways in which struggles can result in misery, tedium and

depression. Struggle is, in many ways, a paradox: it is changed in its outcomes through the way that it is perceived and taken up by each participant. In this respect, struggle is a fundamental human experience, and is thus changed by the human orientation towards it. For example, it is obvious that there is much struggle in preparing for, and running a marathon race, yet for many dedicated runners, a marathon may well be a deeply meaningful or mystical experience. It is also possible that the experience of being in a marathon may strike the unenthused as being a form of torture.

The essential point to grasp is that struggle is integral to the accomplishment of many things in life, and may not be avoidable as a practical matter. Similarly, how one views struggle is not fixed, as there is usually a wide range of responses to a specific struggle, and how it is viewed and managed. An additional point to consider is that not all approaches to struggle are the same in terms of either the benefits or the personal costs of taking up a specific struggle. This suggests that there is always a need to evaluate the question of struggle, and this discretion raises the further question of whether there is an accumulated wisdom that one can rely on in regard to how struggle might best be managed.

### **Making Peace With The Inevitability Of Struggle**

It has already been observed that people will take on demanding struggles, and may even seem to enjoy them. For instance, parents will often tell of the many struggles that their children have caused them, yet conclude that having children is the best thing they have ever done. It has all been worthwhile for them despite the deprivations and personal toll that has come with making a commitment to their children. Few people would say that their lives have been endlessly satisfying, but many would say that the experience has had its share of joy. Clearly, it is possible to make peace with struggles, or at least with some of them.

Some of the conventional advice that one might receive on coming to terms with struggle is worth remembering, because it has a long lineage in the common experience of many people. For instance, it is commonly said that we should try to ‘pick our struggles’. This often means that the struggles that we have taken on, consciously and freely, are easier to bear than those that are imposed on us. It also suggests that some struggles are not suited to us, and we would be wise to evaluate the struggles that have the right fit with our lives, capacities, and motivations. In other words, there might well be valid struggles that ought to be taken up by someone, but not necessarily by us. Conceivably, some struggles might so damage and devastate us that there is ample wisdom in avoiding them.

Some struggles may simply lack meaning and purpose for us, though they may well interest and motivate others. In this regard we may feel a certain ‘calling’ to some challenges, yet lack that feeling in regard to other struggles. This may not be a case of the inherent merit of a specific struggle so much as it is a measure of its fit with our own unique life purposes. This is often evident in the unconventional nature of the life-calls of some individuals, as well as the extent to which many people are deeply

content with the conventionality of their lives and struggles. The term, 'each to their own', is an expression of this wisdom.

A more elusive challenge is posed by the problem of adversity. It is one thing to work towards selectively taking up our own personal struggles, but it is another to have struggles descend on us unbidden. Adversity need not be seen as unnatural, though when it is, the temptation would be to see oneself as a victim of misfortune, and perhaps even the target of malignant forces of some kind. In some cases, a person might feel helpless or irreparably damaged in the face of a catastrophe, and this sense may never leave the person who is traumatised by misfortune.

Alternatively, one can sometimes gradually suspend judgement about the underlying character of adversity, and resolve to await the insights that time might provide regarding the ultimate meaning of an adversity. In this regard, unsolicited adversity, as an aspect of struggle, can be managed just as voluntary struggles can be. There are many people who will attest to the unexpected or hidden benefits of adversity, though such adversity was never sought. Rather, the person involved gradually came to see the adversity in a new light. Knowing that this shift is possible can often open up people to new prospects.

Moving towards reconciliation with the struggles that one faces, or has chosen, normally involves a willingness to sacrifice, and to maintain the kind of commitment that ensures that the struggle will be meaningful. For instance, if the nature of a struggle that a person had resolved to manage, were a decision to care for a parent who had suddenly become dependent, then that commitment would most likely mean the foregoing of many desirable things that the person would have done were it not for the new responsibility. In addition, the person may well be taking up new, and possibly unattractive duties, which are related to supporting the dependent person. This combination of sacrifice and commitment might well come easily to some people, but for others it may be a substantial struggle, particularly if there are tasks or sacrifices involved that are alien to, or uncomfortable for, the person who is taking up the struggle.

The ways of reaching peace with one's struggles are too personal, existential and specific, to be reduced to a formula. On the contrary, it is a quintessentially human task to decide one's path in life, including which struggles to take up and which ones to let go. 'Mindfulness' is much closer to what should be aspired to, rather than to proceed by imitating others, or by following only well-travelled paths. The struggle is a burden in its way, but it is also an opportunity to regain the direction of our lives again and again, as we confront our struggles and guide them to resolution.

### **Reflecting On Where The Struggle Is Located**

The culture in which we live helps to shape us both inwardly and outwardly, giving us values, priorities and views of our world, that orient us to what is important and fundamental about our lives. Cultures are not infallible in this regard, and often mislead us about what is good and worthy. Cultural beliefs and values influence how we approach

our struggles, and in the process, provide us with ways in which we evaluate how we are doing. For instance, in a materialist culture, such as our own, the acquisition of physical comfort, possessions and other forms of material wealth may well provide many people with a sense of what the 'good life' is. Yet, if we reject these as measures of a 'good life', then the struggle we may face might be one of being culturally marginalised, at least as it relates to the primacy of materialism.

In relation to where we locate problems and solutions, we are also guided by our culture. In an externalised culture such as our own, which exalts the tangible world that can be objectified, measured, quantified and manipulated, it should come as no surprise that we are often biased towards seeing problems as being located 'out there, in the world', and apart from ourselves. Naturally, if we see the problem as 'out there', then that is exactly where we will solve it. If, on the other hand, we see ourselves as part of the world, subjective, partially-invisible and not solely our material being, then we will look for solutions that are 'in here', involving our own consciousness and personal values, and will draw upon remedies that are not simply material in character.

In this regard, there may be problems that surface 'out there' in our visible world, that have their origins inside people, and arise from what is going on with their inner life. Anger, despair and a sense of hopelessness about justice may well fuel desperate actions by deprived people. Yet, on another level, the conditions in the world that have produced these perceptions may, in turn, have arisen out of the inner life of people who have created a social order that favours them, even as it disadvantages others. Each is creating an effect on others 'out there', whether they realise it or not. Nevertheless, remedies solely focussed 'out there', and cut off from authentic personal changes 'in here', may well create unhelpful results given the fundamental origins of the difficulties.

This logic would illustrate why it is dangerous to impose our view of reform and remedies on other people, as it may well construct goals and obligations for others while leaving ourselves untouched. This is not an abstruse point lacking practicality, as there is not only an element of hypocrisy in burdening others with responsibilities that are more properly our own, but there is also the unconscious disengagement of people from the effects they are creating in the world. When we are right, and everyone else is wrong, is it any wonder that they can never be right. Equally, when we are willing to be engaged about our place in the world, then it becomes possible to be effective in that world.

This paradox can be seen in the subtle distinctions between whether the world needs 'more' or 'better' by way of a class of solutions. The former is normally a quantitative term, and the latter a qualitative one. For instance, is the poverty of so many people in our world to be solved by simply having more, or will it also require that we all be better people? Is the poverty of people simply because they have less, or is it partially relational, in that others have more because they are favoured by the social or economic order? If the answer is that poverty has nothing to do with the conduct of the favoured, then the poor have only to be inventive about getting more. If, on the other hand, poverty could be seen more as a societal phenomenon, then another class of solutions opens up

that may require us to be 'better' people, and to subsequently do 'more' of some particular things.

Many of us are instinctively drawn to the impulse that if we just had more, then much would be achieved. We often long for more money, more people, more interest, more programs, more power, more time, more support, more expertise, more science and so on. We are not deluded in this regard, as many of these could be beneficial. However, we need to consider the further question of what the origins of 'more' are, at their core, and how this might be mobilised. Without a commensurate interest in the question of people struggling to be 'better', then good outcomes are unlikely to materialise from their invisible inner recesses within people. 'More' and 'better' are both dependent on what is, or is not, happening within people. If the assumption is that there is at least some good in people, then it may not be too farfetched to strengthen this idea and to resist its dilution.

Not surprisingly, poverty would be altered considerably by the strategy of people asking themselves how they could be better in relation to others, as well as by the poor and the privileged alike committing themselves to doing more of what is available for them to do. The poor solely blaming the rich for their misery may be as unproductive as the rich blaming the poor for their circumstances. However, when both the poor and the rich want to see their own part in the problem, the problem then becomes one 'in here' for both groups, thereby making its eventual resolution more probable, conscious and potentially just.

Recognising how we set up problems and solutions does not resolve the fact that we need wisdom in our choice of the values that guide our conduct. However, this recognition does let us see that we all face problems regarding our own authenticity and our need to be 'better'. It may also help us to want to know others, and to understand what makes them work. If we can work together, and build some measure of commonality, then many problems 'out there' may yield, by degree, to our collective efforts. On the other hand, there can be no collective efforts unless there are first some personal inward changes, in all of us, in terms of our willingness to relate to others. Our collective progress inches forward only to the extent that each of us sincerely works to be a better person.

## **Examples Of Struggles That Still Await Our Further Commitment**

As long as there is such a thing as 'we', there will be prospects for shared struggles of all kinds. The needs of human beings are so persistent and diverse, that we are constantly confronted by circumstances that are compelling. The merit of a struggle is not in its prominence or scale, but rather in the ways in which it draws upon us to be our best. There are many such struggles, at this point in time, which remain as relevant now as they were in other periods of our history. It is important to appreciate their universality, as well as to note with gratitude the contributions of those who came before us, making it possible for us to achieve the results we can garner today.

## Values, Ideology And The Dignity Of The Person

It has been a recurring theme in the struggles of people with disabilities, and their allies, that they have had to make relentless efforts to have their humanity fully recognised and appreciated. This is true today in that we all still hold stereotypes about people with disabilities that are dehumanising, diminishing of their personhood, and often harmful because they cast people into devalued social roles. While it is true that the overt nature of this kind of abuse might be less acute than at other times in history, the negative messages are often muted, rather than eliminated. At the heart of this kind of abuse is the preference, which we all harbour, for seeing people as somehow 'less than' ourselves. Although our actions and beliefs might be unconscious, this does not mean that they are unnoticed or without effect. On the contrary, those who are treated in this way are exquisitely sensitive to how they are perceived and valued. One only has to ask people with disabilities to share their stories, to hear distressing vignettes about how many people still behave towards them.

Nonetheless, gradual progress has been made in countless small ways, mainly because we have become more attuned to the way that our attitudes influence our behaviour and patterns of life. Through different kinds of consciousness-raising we have been helped us see people as they actually are – as people rather than as socially distant categories or objects. This, in turn, has helped to break down barriers so that it is somewhat more likely we will see a person as being unique, with the many strengths and shortcomings that beset all of us.

## Respecting The Voices Of People

It is puzzling to see how often decisions are made *for* people with disabilities rather than *with* them. This suggests that many of us still do not recognise that we need to fundamentally change our behaviour so that what people with disabilities want and need is determined by, and with, them. Although we might mean well in our actions that take over people's lives, this still results in conduct that most people would find offensive and paternalistic. Worse yet, we structure this paternalism into habitual and institutionalised patterns that leave people with disabilities dis-empowered and hostage to the whims of others. It is ironic that we do this whilst undeniably believing that we are essentially showing respect to those people.

Such an obvious violation of how people ought to be treated gives greater urgency to the question of whether we are truly in 'right relationship' with people who have disabilities; as long as we are still seeking 'right relationship', there is always the hope that we can eventually do better. However, we cannot let our voices grow so loud that the voices of people with disabilities go unheeded or need to be loud and angry to be heard. We need to be quiet and small enough so that even voices that are merely a whisper can be heard. Occasionally there is a tendency to see the solution as making the voices of people with disabilities louder, confrontational, and more aggressive, which may be an imposition, of a style that is not their own on many individuals.

A simpler answer would be to let the ‘voice’ of people with disabilities be what it actually is, in all its diversity. A wealth of different people and voices lies behind our broad labels, and we are going to have our work cut out for us if we are to redouble our efforts and listen to people, with the right spirit.

## **Supporting The Supporters**

Few people would quarrel with the assertion that family and friends still remain the most dependable form of social support for people with disabilities. While we have attempted to substitute for these natural supports with paid human services, few people are satisfied with the outcome. This is for good reason, as most people recognise and value the special qualities of concern and commitment that come from people who love them, as opposed to people for whom it is a job.

Perhaps it is because we have placed so much energy during the last decades into building up formal systems of support, that we have lost sight of the more fundamental role and contribution of informal supporters. The service system now consumes proportionately more resources than those that go to nourish and support families and friendships. One only has to look at spending levels on family-support to see where the real priority is. Unless families go into acute crisis, they may be neglected. We are much better at getting people into formalised professional services than we are at supporting them through their natural networks, even though their families and friends may be the only ones who have shown a lifetime of commitment to them.

It is not clear how we might do better in this regard, because simply spending more money on families and other natural supporters may have the unintended consequence of turning families and friends into “de facto” staff. Nonetheless, it should be assumed that we would eventually make progress on this question of supporting the natural supporters, if we turn our attention to it. We may have to learn that many natural supporters should be seen as potential innovators, allies for change, and advocates, if we are to begin to more fully grasp how this potential could be better husbanded. When natural supporters become a more fundamental part of discussions about what is a better way of doing things, then surely they will be properly recognised and respected.

## **The Need For Moral And Principled Leaders**

It has always been true that we have needed leaders who have coaxed us towards discovering the directions that would result in real progress. We will always need leaders who not only effectively lead us in the right direction, but who also do so with integrity. Such leaders are not going to appear just because they are needed, and naturally, they will pass with each generation. Not only must we identify, recruit and orient new leaders but we must also show concern for keeping our present leaders renewed, relevant and challenged. Many people think of emergent leaders as simply being restricted to people who gain titles, but this is deeply mistaken, because leadership can come from any social group including people with disabilities, their families, employers, bureaucrats,

academics, or ordinary members of the community, given any issue and the people who might step forward to act on them.

What may need to be appreciated is that we can either assume that such leaders will magically appear just because we need them, or we can take a more prudent course and proactively identify, recruit, develop, support and renew potential leaders long before they are needed. We can see this need now, as a whole generation is preparing to pass from the disability field. So little has been done to prepare the upcoming generation for the leadership challenges that they will inherit from the present generation. Without the catalytic presence of a new generation of principled leaders, it is predictable that other influences will enter this leadership vacuum. Perhaps some of those influences may turn out to be benign or even progressive, but it is useful to consider what may be lost if they are not. We have struggled hard for our values and for the reforms that they have brought about – it would be a pity if these were left undefended through the absence of leaders who are able to recognise and appreciate their importance.

### **People Who Will Take The Hard Stand**

There are always times when it is important to have people who will stand on principle, and challenge society to live up to its better nature and traditions. Such activists may be formal or informal, local or national, prominent or obscure, but they will be known by their willingness to embrace the crucial issues that must be faced, and do so in ways that go to the heart of issues. It is an often-quoted observation that *one person can save a city*, and so we are not talking about a great mass of activists, as much as we are about the presence of activists and advocates of great distinction, principle, and vision.

In the case of moral leaders, our prospects for having principled people are increased if we lay the seeds for their formation and maturation well in advance of the times of tribulation in which their courage, vision and character will be most needed. While it is true that such people are fundamentally born, not made, it is also true that these natural gifts are more likely to come into play when they are recognised, valued and supported so that they develop to the higher levels of their potential. If we are to have social movements that are vigorous, challenging and positive, we will need advocates who will act as the stimulus for such movements. Taking the trouble to ensure that strong advocates will be there when they are needed is clearly worthy of struggle.

### **Service Structures Inspired By 'Right Relationship'**

The chaos of our modern service systems is all too evident to the people who rely on them and who have to work in them. Despite our best intentions and the application of vast resources, these systems are very difficult to keep on the right path. When they lose their way, it can mean the rupture of positive relationships between services and the people they serve. A breakdown in the ethical foundations of the relationship between services and those they assist will undoubtedly require a great deal of thoughtful action to build, and rebuild.

It is not that such ethical relationships cannot exist, as there are innumerable instances where these relationships are wholesome or even inspiring, however, the scale, complexity and powerful vested-interests in these systems provide huge obstacles for keeping the proper alignments, which will be needed to meet the test of right and honourable relationships. It can be anticipated that keeping such systems honest, whether from the inside or the outside, will provide committed change-agents with ample opportunities for struggling with the many issues that are involved.

## **Improved Theory And Practice**

It is worrying that we hear so many complaints about the quality of community services, given how hard it has been to get them established to a point where they might become a more reliable resource for people with disabilities and their families than formal service systems. At the same time, these complaints and dissatisfactions can guide us to where further work is needed, or where our theory about practice needs to be revised. It is always painful to have our contributions criticised, but we can draw important insights into how we might do better by attending to the lessons that lie behind the criticisms. The reality is that we need to keep evolving, and that many of our service models, and the theories behind them, are increasingly out-of-date.

Some hope can be drawn from the fact that our potential for learning today is as strong as it has always been. In addition, we have witnessed all sorts of advances in the past four decades, in both our thinking and practice. The state of the art has noticeably improved on many aspects of service. Nevertheless, potential of this kind alone does not do the job. We need people who will harness the potential, so that people's lives are changed for the better through their contact with services. In fact, we need a whole new generation of people who see their mission as being a fundamental assault on all the reasons why human services have not been of good quality. Naturally, this is an intimidating prospect, but not beyond our grasp.

## **Strengthening People's Ability To Innovate Usefully**

It is obvious that many people have the capacity to innovate, but are blocked from doing so, by their own limitations, and by the many discouragements that may be present in the environments that they have to contend with. It is also obvious that innovation is not a kind of fixed-outcome, but has a more variable character. With the proper stimulations and support, a surprising number of people can participate meaningfully in formulating, and negotiating into reality, many striking innovations. We will always need creative people and supportive settings that foster innovation. We will also need the allies of innovation, who can provide the kind of political and situational leadership that permits innovations to be to be conceived and helped to reach the practical maturity of their inherent potential.

These innovators, and the constellations of like-minded people in the process of change, are not random in their occurrence, and it is possible to deliberately envision and

nurture them. Doing so is quite a struggle, but there are strategies that can be thoughtfully applied, accelerating the likelihood of successful innovation.

## **Relationships And Social Belonging**

It is common to hear people speak of the value of social inclusion, although it was not so long ago that support for the segregation of people with disabilities was widespread. This is encouraging because it shows what can be done when people go deep enough into change that long-term habits such as patterned social exclusion fade from prominence. This does not mean that we do not have problems of this kind now, as we can see that people with disabilities are still not welcomed whole-heartedly, that many lack the kind of sincere personal relationships that they need, and that they simply do not seem to have a valued place in many aspects of our community. These are crucial thresholds that we must move beyond collectively and individually. In fact, each of us would be well advised to actually live social inclusion better, rather than concentrating on exhorting services to do better on this issue.

This will begin to happen when we are helped to see the need for each of us to be personally present for people with disabilities when it comes to real relationships. People with disabilities need to become more a genuine part of our personal and intimate lives, even while they might still remain only legally tolerated in public life. We do not need to be 'perfect' in our relationships, as that kind of pretence would be unhelpful. Instead, relationships, and the character of social and personal presence must be authentic, unfeigned and hopefully enjoyable. So we face the twin challenges of 'more' social inclusion and 'better' social inclusion; we must successfully face the inner challenges of social inclusion as well as the outer ones. Neither has been easy thus far, so it can be assumed that this next stage will be a struggle.

## **People With Disabilities And Their Positive Contributions To Our Lives and Communities**

It is quite one-sided to dwell unduly on the neediness, deficiencies and problems that are faced by people with disabilities without giving balance through an appreciation of the actual and potential contributions made everyday to us, as individuals, and to our communities. These contributions are often exciting, beneficial and worthy of much credit. If we never draw attention to these contributions we might walk right past many accomplishments as if they did not matter. By concentrating so much on what people have difficulty doing, we will miss what they are doing that is of value, and of knowing what people want to do with their lives.

The stereotypical attitudes that we have undoubtedly make non-disabled people feel good about themselves, at the price of masking the goodness and virtues of people with disabilities. By using them to feed our own psychic needs, we may find that the potential virtues of non-disabled people become 'deformed' by our own neediness. The obvious solution for this is to re-dedicate ourselves to the task of recognising goodness wherever we find it, and being sure that our celebration of virtue is fairer to individuals

whose disability overshadows the real identity of the person. In this regard, to be able to receive what is given may be just as important as to give what is needed.

## **Conclusion**

There are still many worthwhile struggles that would ask the best of us, and provide us with much satisfaction along with the difficulties. Struggles ask much of us, including a willingness to be found wanting and to fail at things that we care much about. It is safer, in many ways, to walk away from struggles, as we will never have to take painful risks. Even so, being personally safe may not be the highest value, nor may it be where we find the most authenticity and satisfaction in our lives. To struggle may well be the only way we can grow and develop, and it would be a pity to turn away from our potential because of what struggle requires of us. As we have seen in this exploration, the inner struggles are the most defining ones.