Becoming Clear about Achieving a Life with Others

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Abstract:

In this paper I will address the combination of two main forces: one the societal preoccupation with promoting the self, the other, the common idea that the community is to blame for the hardships disabled people face. The paper contends that the emphasis placed on these two aspects distorts the nature of services and the expectations placed on communities, which is not just unproductive but at worst, fuels the breakdown of adaptive communal life. The paper offers an orientation towards revealing the gifts and strengths of people as they are supported to participate through valued social roles while also ensuring the community benefits from the presence of people so that authentic reciprocated relationships can be experienced by all.

Setting the scene. The Good life isn’t a single point in the future. It can occur within a larger continuum of possibilities. Michael Kendrick at this conference explored the kind of custodial service possibilities we want to avoid. For many the question is how. Michael suggested we select values that are life giving. With that in mind, we want to examine developments at the very valued end of the continuum, that part that many of us love and are deeply invested in and harder to break with should we see a future need to do so.

This end of the continuum too can distort our picture of the Good Life for people as we explore the awful possibility that not everything that is valued by a culture is necessarily good for people.

The way we see a problem affects what we do about it. Since the time of Henry VIII and the sacking of monasteries and other Catholic properties, the poor, the destitute, orphans, widows including those with disabilities have either fended for themselves on the highways and byways or housed within poor houses largely isolated from the main economic activities of society. Indeed many pressures existed upon the ordinary person such that whole populations of people in Ireland, Scotland and large parts of England and Europe were kept in a state of perpetual poverty so that the lords and upper classes could extract wealth from them. So disdained were the lower classes that for many, their meagre efforts to obtain food were deemed criminal acts deserving expulsion to distant lands.

While these things are in our historical past, other parts of the modern world still experience “extracting economies and absolutist governments” (Acemoglu & Robinson 2013) that enslave populations to prop up the grandiose lifestyles of elites, whether as dictatorial leaders or regional warlords. Countries such as North Korea, The Congo, Zimbabwe, Somalia and much of South America have been held back by political powers and economic policies that virtually enslave whole
populations. But even in the West there is such a growing separation between the rich and poor, where real wages have actually decreased for workers over the past 20 years while the wealth of the rich grows exponentially. As an illustration, the top 400 wealthiest individuals in the US make $97,000 every hour, (Stiglitz 2013) whereas the basic wage in the state of New Jersey is $2.13 per hour, before tax translating into $28 per week for a full time worker. Whole working families can often only afford to live in just one room. (Foreign Correspondent, ABC TV 23/10/2013). Support workers in many states in the US make no more than $7 per hour.

Many devalued people are caught up in this separation as well; they are almost always poor, a condition that brings a multitude of disadvantages, including the potential for earlier death. Inequality such as this is growing wider by the day and is possibly the major reason for the degree of economic instability we are experiencing across the world (Stiglitz, 2013). Not only do economies favour the wealthy, but so do political institutions that also enact laws and provide favour to the wealthy. As Joseph Stiglitz commented in relation to this trend is that we are heading for government that is “of the 1%, by the 1%, and for the 1%”.

This can be said to be a society wide, even worldwide trend that impacts itself one way or another, on everyone.

How should one respond to such a cultural trend? What could we do? It depends on the way we see a problem as to what we do about it. If we were wealthy, we would probably want things to stay the same or swing even more in one’s favour! We’d even make up a theory as to why this is good for everyone...like a “trickle-down effect theory”...“if I get rich, so will you” even though there is no evidence for that.

The rise of individualism. Another trend affecting the west, but is also being felt in other parts of the world, is the rise of individualism. Since the sixties people have thrown off the restricted ideas of the past, the expectations of authorities, families, tradition and even nature to embrace a new freedom based on becoming and doing whatever I want, “as long as it doesn’t hurt anyone else”. This “iworld” (According to Dale Kuehne, Associate Professor of Politics at Georgetown University) seeks three things: 1) control over nature, 2) control over authority and 3) the maximum freedom to do and be whatever I seek—that is, to remove every barrier that restricts the pursuit of any desire. Even our products are brilliantly labelled to reflect this emphasis: ‘i_pad’, ‘i_pod’; ‘i_phone’; all in an i_world.

Such emphasis elevates choice as the only requirement. The i_world trend insatiably pursues a wider and wider array of choices. Consequence is not considered; morality is non-existent; there is no judgement. Where marriage and sex was once based on a covenant, it is now based on consent, but a consent that can shift in a moment as desires abruptly change. “Relationships” can start and end with a text message, disconnected from wider family networks that once ensured some degree of survival.

Kuehne believes there are three taboos that govern this:

The first is “One may not” criticise someone else’s life choices or behaviour;

2. One may not behave in a manner that coerces or causes harm to others; and
3. One may not engage in a sexual relationship with someone without his or her consent.”(pp 71)

These 3 taboos have become the new rules for social engagement and are taught from an early age and are presented throughout entertainment and various other media; the first taboo being the basis for political correctness (and may account for why staff are reluctant to give people feedback about the unforeseen consequences of their choices).

Just as inequality has a massive impact on employment and income, what impact might individualism have on the hope for relationships, a hope we thought “inclusion” would satisfy? Much like the wealthy favouring inequality, many of us might see the iworld as bringing enormous benefit – but will it always?

For instance, the iworld creates both a panacea of expectations (after all, it only takes ‘consent’) but also insecurity; few relationships are based on commitment or obligation (except perhaps parenthood). A world based on choice lacks certainty; no one can be certain that anyone will stay with them. One must keep one’s options open, never placing one’s hopes for fulfilment beyond the current if fleeting pleasure you bring me. As such, intimacy is assumed to be synonymous with sex and given the pace of potential dissatisfaction, one better seek such intimacy quickly lest one’s newly found partner tire of waiting or turn their attention to another seemingly more attractive and willing prospect.

Thus while the iworld embraces sexual and relational freedom as the highest ideal it is clear that a certain world-weariness and latent insecurity functions as a hidden undercurrent (ibid p79). This creates an urgent to seek another contact that somehow provides proof that one is worth knowing–if only for tonight. People in the iworld do desire more than this, but they also want the freedom to pursue relationships of convenience (ibid p81). No wonder being cool and sexy is almost a mandatory requirement for mere survival for young people.

While we hoped it would be easy just to find someone to share a flat we also find relationships in an iworld especially fragile. The only assurance is that they will stick around as long as one or the other desire to. No one can expect (in the iworld) long term relational security. All relationships become ones of choice; old relationships based on obligations – such as extended families, are potentially in crisis.

It is interesting to contemplate how just these two powerful trends of inequality and individualism (iworld) play out upon societal structures, communities and people.

**How does the service system respond to this?** What does seem evident is how the service system takes notice of wider societal trends. Services consistently reflect but also amplify wider societal trends, possibly because they enact them divorced from other diluting cultural influences. For instance the indifference society had towards the orphan after World War 2 got played out in services who felt they were free to communicate that indifference through appalling hardship, cruelty and deprivation and for their hierarchy to turn a blind eye while doing so. No actual mandate came from society, but the value trends permitted the service system to act with impunity.
What about the iworld? Many services and their workers, having absorbed the values of the iworld have specifically embraced the first taboo and often extended choice (assumed to be the ultimate expression of freedom) irrespective of its consequences on the people they support. The iworld has effectively become their moral operating system; their de-facto religion of sorts. Some become fundamentalists and as such absolutely certain as to the value of their position. Agencies must spend money on values exploration exercises to identify positive values and virtues that might inform their work and partly fill the moral vacuum left by the iworld. But in an i-world such traditionally powerful values as ‘integrity’ and ‘commitment’ come to sound strangely empty and meaningless especially where ‘choice’ commands the ultimate devotion. That first taboo snookers everything. When judgement has been excluded from all human interaction, what place is there for integrity? As workers frequently say to me, “who am I to impose my values on someone” not appreciating that they already have. (Whether one acts, or doesn’t act in someone’s life, they are already imposing values—one just can’t get away from it).

**Collapse of traditional structures and the effect upon the ‘poor’.** There is a particular problem the iworld can create for people who formerly derived direction in life from external structures and traditional lifestyles. When the external structures collapse or are abolished so too are their ways of life. For some this can be completely emancipating, like freeing captives or slaves. For others who had come to rely on such structures as a compass, its loss can be anything from dysfunctional to catastrophic (Douglas 1973).

I recall when a particular institution in Victoria closed some people were moved into two person accommodation with very little staff support. Of course all the daily routines of institutional life disappeared and therefore so did the usual cues that signalled the daily pattern of life, even if it was culturally bizarre and strange. In several instances people took to sleeping all day and watching TV all night—because they could! One man rang me several times at 3am having mistaken the usual patterns of life of everyone else. In one instance, he wanted to know if I would come to his birthday party, which was still 2 months away. Another man rang one of the sex lines he saw advertised on TV and raked up a bill over $4,000 in one night. Other people with intellectual disability ring such lines because the people on the end of the phone will listen as long as the caller keeps paying. Even those lines refuse the calls when its realised they can never repay.

The Centers for Disease Control and Prevention in the US have reported that suicides rates have risen dramatically, up nearly 30 percent for those aged between 35 and 64 between 1999 and 2010. Interestingly, the greatest increase was an alarming 49% that just happened to take place in Oregon, the first state to legalise doctor assisted suicide. Those who want to legalise drugs are often those who have disciplined approaches to drug use, whereas for poorer less educated classes, drugs completely undermine any semblance of normal life and destroy every relationship. The same with gambling; those with poorer education have been shown to gamble more regularly and lose money they can less afford to lose. In other words, the iworld is jettisoning many natural if traditional symbols that served as guiderails for people’s behaviour for generations. **Is this yet another form of war upon the weak?**

The wealthy, higher educated people tend to maintain certain habits and disciplines that sustain – at least for the moment an ordered and functional life (unless you are a Kardashian or Lindsey Lohan).
They may approve of couple’s living together, but their marriage rates are as high as ever. The poor, less educated classes having lost the influence of external structures receive the full impact of a collapsed lifestyle, which is devastating to a functional and adaptive life for them and their families. (Reno, 2012). The physical and social devastation of many Australian Aboriginal communities are a case in point.

Are there implications here for disabled people when freedom is defined as doing whatever you choose? Is the Good Life dependent on internal habits and disciplines that are likely to produce the Good Things of Life?

Am I getting uncomfortably close to that first taboo?

But clearly, what gets promoted as freedom and choice produces incredible disaster for many people, but we don’t seem to connect to the wider societal trend that produced it. We simply push for some new low-level law to put a stop to some specific rampant behaviour, like plastic cups in pubs to stop ‘glassings’ or mandatory reporting while the incidence of child abuse explodes throughout our communities.

Exercising freedom sometimes involves the practiced ability to say ‘no’. Saying ‘no’ is what truly makes you free, except ‘no’ isn’t something the iworld expects to hear. (Jeep: ‘Don’t Hold Back’; Nike: ‘Just Do It’).

How will disabled people and their supporters respond to this illusion of freedom?

**What has devotion to the iworld done to our expectations on the community?**

I recently attended a 21st anniversary of the closure of an 135 year old institution in Australia. One of the speakers – a professor of disability studies – claimed that the institution was caused by the community. I still hear this frequently today as some workers assume a militant stance with respect to the community as they wait—perhaps impatiently, for unconditional acceptance.

We do know that society can certainly devalue people and responds to the values prevailing at a given time about who that should be, but it is largely structures that enact these devaluations which results in the large scale wounding of people. It is through the structures of society: health, education, corrections and human services where direct or indirect neglect and harm of people occurs. You don’t have to be in an institution for that to happen. It’s been that way since the 16th Century. At the turn of the 20th Century society was so captivated by science and the theory of evolution in the form of “Social Darwinism” which gave rise to the Eugenic movement. Political, academic, judicial and scientific structures colluded in enacting eugenic policies with devastating effect and with the invention of the IQ test literally arresting and sterilizing people diagnosed as feeble-minded while attaching diagnostic labels of Moron, Imbecile or Idiot (Black 2003). It was systems that led to the large scale institutionalisation of people that lasted till the 1980’s with many people yet to escape them even today.

To get to this point in history and blame the community for the lack of “inclusion” and demand that the community fix it, could be seen as just a bit rich; a kind of guilt trip placed upon others, the
clanger we could trot out at gatherings where we could play the victim and wait for others, so that I might claim my rights through the obligations placed upon others.

Because disability today is regarded as a lack of adaptiveness by the environment to the needs of the person, and it is this that makes one disabled, it is perhaps not surprising to find that our main concern with ‘Inclusion’ is how long the community will take to accept someone. That is, there is some progress to remove the blame off people (though blaming individuals for responding naturally to the gross violations in their treatment is still common) but seeing disablement as a purely environmental issue has encouraged us to shift the blame to the community, as though it is singularly responsible for all that is missing in someone’s life.

Some, who perhaps love the iworld say community acceptance should be unconditional. Then you would have to invite back the hoons, the murderers, looters, robbers, the breakers & enterers, the men who beat and kill their partners, the rapists, the child molesters, the corrupt politicians, defrauding business people, the girls who fight, the paedophiles, the drug pushers. To be a community implies definition—something you stand for and against; you have to draw the line somewhere. And communities can become fearful when there is too much change. Cultures by definition do things a certain way, otherwise they wouldn’t be a culture. The call for more diversity carries with it the possibility of loosening cultural ties and commonalities that actually bind us together. The iworld has no commonality except the mutual freedom to choose whatever I want.

Might we consider that demanding an “inclusive community” poorly defines the task before us? Indeed the Good Life is in the community, but we may be using it as a scapegoat for the ills of the system and the dysfunctional values of a wider culture, that communities everywhere are struggling with. What should the community do for disillusioned youth, high unemployment, child abuse, and marginalised people? I don’t think the community caused those problems, but it certainly wears the results. In our frustration we may have made ‘the solution’ ‘the problem’.

Did services have a role in “teaching” the community how to see & treat people? I suspect the community is already largely inclusive. It’s been that way for a very long time. It’s just that there are conditions, many of which were historically violated by services who through such violations created false impressions of people. You know what they are, the number of people grouped together and the incoherent composition of that group, neglected or bizarre appearance of people, inactivity and vast idleness or just silly & wasteful activities instead of roles, staff authority and dependency-making instead of positive complementary roles, and much deeply negative imagery.

What might be done that would more accurately reflect an understanding of where the problem lays and what an effective solution might look like?

We could stop accusing the community of being the problem and showing up with problems for the community to fix. We could come bearing gifts; the gifts and assets of the people. Communities are not interested in more problems, its interested in the capacities and gifts that people bring.
The service system’s focus on the individual. But it is here, the iworld starts to bring its dysfunctional influence. One celebrated aspect of the service system absorption of iworld values is the focus on the individual service recipient and the concerted exploration of individual preferences. This is a significant departure from the past where one size fits all (when it didn’t fit anyone). We also know that a service is more likely to be relevant for someone the more it is customised to their requirements.

However, the iworld emphasis is not so much exploring who one is (their gender, race, ethnicity, culture, language, family, region, talents and gifts) but who one wants to be. In other words, the iworld suggests you can be anything you like, such that a person might craft an identity of something the culture has never seen before rather than to discover one’s real identity. And given the iworld’s resistance to nature and authority, both are seen as unnecessary restrictions of an unlimited array of choices. One can now pursue choices never before imagined and indulge every impulse that in past ages was defined as a vice and therefore to be resisted. In the disability world, one can even recruit an entire team of people who meet regularly just to discuss your future (which is a great strategy if you have never had a future) but, on the other hand, can be seen to be fully consistent with an iworld expectation. Person centered plans that originally stemmed from the wish to keep the self-seeking agendas of other parties at bay can now become a new iworld tool for ensuring things occur in ways that just suits me.

Wolfensberger wrote about the iworld too, though he called it ‘modernism’ and his view incorporated 5 main features he referred to as the “Pillars of Modernism” (Wolfensberger 2005)

1. Materialism, (2. Individualism) 3. Sensualism, and 4. Externalism--having no internal life, just reliance on a continuous diet of external input, 5. and living only in the moment without a sense of the past or of future: he called ‘Here & Nowism’. You can see how each feeds and feeds off the other and contributes to the iworld greatly.

He believed the results of this would affect people’s mentality and would destroy their capacity for 3 things: 1. rationality, 2 self-control and 3. morality. If this was embraced enough he also foresaw that it would threaten the very functioning of communities and of wider society. He called this requirement “Comitous Polity”: A way of people living together in a nation &/or under a governmental structure in sufficient agreement to do harmoniously.

He believed that if modernism obtained sufficient foothold, it would destroy comitous polity; it would destroy the capacity of families and communities to remain adaptive environments for people because the agreement, at all levels, would collapse as in Washington recently and glaringly in Syria.

Can I dare make it plainer: If I demand to have my person centered plan from my person centered thinking group to have my person centered way of life (and to the degree that it is something no one has ever seen before) are we making a small contribution to the unravelling of communal life?

We are not quite there yet are we, though there is plenty of evidence of massive unravelling across every community. In Australia we have 40,000 children removed from their own homes because their parents are too dangerous for them. They are now in foster care, which time and again has
been shown not to be particularly safe either. There are so many children remaining unsafe in their homes that the authorities can’t even get to them because of the sheer numbers.

Communities have always existed through mutual obligations to each other, not in having my own way.

Being in a community is about having enough in common with others that I can also be myself.

How does this occur: People are known because of their relationships; “that’s Jack Armstrong’s boy”, “the Granville kid”, “ah, she’s the swimmer”. Our primary roles are the ones we are born into but which can be added to as we get older through new significant associations such as best mate, closest friend, and spouse. They form a primary foundation to who we are and how we are seen by others. They are connections we make because of the close ties that are formed through the things we have in common and the bonds of friendship we make especially if we go through tough experiences together.

Then you belong.

One of the best ways of making new primary role relationships is to do stuff with others. Such action based involvements are called secondary roles and it’s through these that the prospects for new primary role relationship are made. You would need a sufficient groundswell of secondary roles (soccer team member, worker, poet, athlete etc) to flow over into new primary roles: new friends. (Lemay 2006) And friends are people you can contribute to because others need you, which for a devalued person could possibly be a brand new experience.

Exercising the gifts one can bring to both primary and secondary roles is an important feature of discovering who you really are and learning how to give to others. Our relationships also take off our rough edges and give us impetus to change & grow—something the world never expects. Being with valued people is a crucial way of counteracting any potential for obtaining a devalued identity. It allows others to see what is true, accurate and beautiful in someone.

Much discussion of ‘Inclusion’ however, seeks involvement as a right; a kind of “threat based” advocacy. But in his recent book, The Good Life, the highly respected Australian Social Scientist, Hugh Mackay writes:

“The crucial test of a life well lived is the quality of our responses to the needs of others. Everything else is peripheral and mostly trivial. From our chance encounters with total strangers to our long-term associations with family, friends, neighbours and colleagues, our connections with other people form the testbed of our sensitivity, our moral courage and our capacity for love. After all, our relationships, whether fleeting or enduring, are the source of life’s richest meanings, but, as we struggle to establish them, nurture them and sometimes forsake them, they teach us that happiness and sadness are mere accidents of our fluctuating emotional state, incidental to the great
realisation that it is in loving we are made whole. And yet love’s work is the hardest work of all, which is why this book is about the good life, not the easy life.

Helen Keller, the remarkable American who, despite deafness and blindness, became one of the twentieth century’s most outspoken humanitarians, asserted that ‘happiness is not attained through self-gratification, but through fidelity to a worthy purpose. On the same theme, the German philosopher Immanuel Kant wrote, ‘Morality is not the doctrine of how we make ourselves happy, but how we make ourselves worthy of happiness’. At the core of both those statements, and of so much of the world’s wisdom, is the belief that happiness is at best a by-product, not the goal, of a well-lived life”. (Mackay 2013, chapter 2)

The great enlightenment philosophers wrote of this time. It is their script we are responding to. Indeed, it is their view of utopia we are living, though I am not convinced it’s very utopian. A culture that is based on ‘I’ and ‘me’ when it used to be ‘we’ and ‘us’? We have never seen it before in the history of humanity. It took until the 60’s to fall into place. But there are significant questions as to how much of it really produces the Good Life.

In the past we responded to the system’s advice to institutionalise loved ones in the hope it was the right thing to do, but look what happened. That should teach us to at least be cautious in unhesitatingly accepting this current edition of utopia and its human service counterpart, both in thinking the world (and its communities) are obligated to include us while I largely have my own way.

We know that when valued people have direct contact with members of devalued minority groups and where such contact is mutually favourable and beneficial, the attitudes towards each other improves. We know that communities are often incredibly willing to be involved with people if we can take care of two major issues that community members can be pretty anxious about (here are the conditions we spoke of earlier): (based on Dianne Craig’s findings in recent research from Latrobe University2010 ASSID Conference presentation and as reported on ABC Life Matters Monday 11th Nov 2013):

1) Can the person fit into the community group.

SRV would ask such things as: Is there a match between the available role and the person – a person role match, Is there a role vacancy in this group? Is the person suited for the role and able to perform at least part of its requirements? Does the person look the part? (Lemay 2006).

2) Can the group continue to function with this person in the group?

For instance, some vocational services brilliantly craft a ‘customised employment’ role that not only suit the person but serves the interests of the business. They emphasise the welfare of the business
in the support of the person, knowing that unless the business thrives the person’s role in the business will be in jeopardy.

The concept of Inclusion doesn’t particularly orient us toward either of these crucial questions, yet both questions are essential to the strategic success of enabling a person to successfully and enduringly be with others. Wolfensberger called this Personal Social Integration, Valued Social Participation (Wolfensberger, 1998). He refused to use the term ‘inclusion’ because it was undefined (it actually lacks an agreed definition), was mostly rights based and didn’t reflect the reciprocity needed for relationships to work. It might be more accurate to describe ‘inclusion’ as a political slogan, or a political goal but one that is strategically inept.

When the people we support are in **ordinary roles**, the community has a better chance of responding in **ordinary ways**.

Yet, it’s also possible that members of the community will sometimes make the same mistakes we used to make. Human services were very good at teaching generations of communities such things as seeing people as eternal children, or as objects of pity or as burdens or as sick and diseased or even sub-human and as menaces. It shouldn’t be terribly surprising that a bloke at the men’s shed says “good boy” to someone of adult age. And rather than a stern lecture on the “21 rules when talking to disabled people”, we just model a more appropriate response. As we have recently reformed many of our practices we are beginning to give ordinary citizens a real chance to know people more accurately—perhaps for the very first time. Disabled people too also discover what the Good Things of Life really means and that amongst many things, it has a great deal to do with contributing to others and **not** with always having your own way. It’s more about being **other** centered rather than **self** centered.

What we do know is that the Good life is largely free and it occurs in the ‘shared space’ of the community not the ‘managed life’ of the service system; it is inextricably connected to unpaid relationships and it’s mostly about the reciprocal **contribution** we make with others. It’s about letting those relationships teach us and shape us and craft us into better people; a reflection of my true self, my moral self, and not just a context for expressing my will and having my way.
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