The Relational Basis of Empowerment

Karl Nunkoosing and Mark Haydon-Laurelut

Editors: John O'Brien and Simon Duffy

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THE CENTRE FOR WELFARE REFORM

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Foreword

This is the second publication in our series – *The Need for Roots*. Like the first *The Unmaking of Man*, it begins by considering the causes of the human tragedy of the abuse and oppression of people with disabilities – especially people with intellectual disabilities.

However this essay takes as its starting point the Winterbourne View scandal. This may not be familiar to readers from outside the United Kingdom, but is yet another example of institutional abuse within 'care settings.' But this time the abuse was not in an old long-stay institution, but in a high cost, modern, private residential unit for people with challenging behaviour.

The authors begin by looking beyond the on-going failure to reduce such abuse through the self-contradictory effort to exert regimes of control, supervision and training on the staff working in human services. They see that this merely replicates the very problems that helped cause the abuse. The official story is that the staff are incompetent, not to be trusted, and so we must make them trustworthy. In this way another cycle of failure begins.

Instead we are asked to consider what we know about what really works. We are offered a compelling account of the power of relationships in the achievement of empowerment.

This brought to mind the work of a thinker whose work has not received enough attention. Hannah Arendt, in her essay *On Violence*, argues that the word power is misused when we apply it to systems of force, top-down control and violence. Power, she claims, can only be created by human beings working together as equals. Her starting point is the experience of the Greek polis – but the authors seem to suggest that we can also see it in proper support – two individuals working together, with freedom and equality, to achieve valued goals.

The authors go further and expand upon the kinds of cultures that are created by different kinds of relationships. This is very useful because it helps us see that it is not just negative images or abnormal or devalued services that encourage institutionalisation and abuse. Instead their analysis suggests that it can be understood as beginning in simple and yet profound aspects of our relationships.

The authors do not use the word love – but it is hard not to think that they are here articulating two aspects of love, true love, both an acceptance of the person, but also a faith in the person and their capacity to live a good life.

Finding the right people or inculcating the right values becomes the central task of organising good support. But this is hard and it is not how the current system works. Instead it focuses on shaping behaviours, fitting people into organisational structures and setting policies.

To find an alternative the authors suggest we think about the stories we do tell and the stories we should tell. If we accept the need for stories to be rooted in the values of empowerment, in a positive regard for both the value and the prospects of the person with disabilities, then certain stories are helpful, but many others are toxic. Many of the current stories told within organisations, policy-making or the general media merely reinforce the cultures of punishment, control or protection that we want to avoid.

This is a particularly useful way of interrogating modern policy-making. It is useful to see that there are implicit negative meanings in all our policy stories about commissioning, service systems, regulation and consumerism. Even while policy-makers use words like capacity, citizenship and empowerment they then strip those words of meaning by the stories of commerce and control within which the words are used. Good words with no deeper roots become empty or even harmful.

We could pursue this argument further by looking at one of the most modern themes in public policy. For example, the term 'personalisation' is used to refer to many attractive practices – but the very term 'personalisation' strips those ideas of meaning by focusing not on relationship, power and citizenship – but on the need for organisations to offer more personalised support. And so people become objects upon whom others must act – but now in a more 'personalised' way.

The merits of this essay are many but two stand out. It asks us to start from the basics of our humanity – how we are with each other; and yet it shows that this can be a very fruitful way of understanding many of the problems we struggle with today in complex welfare systems. This must be one of the roots we must value more – our relationships with each other.

In addition the authors reinforce the value of stories. Again it is interesting that Arendt also wanted to remind us of the value of stories. Within academia and policy–making there is great resistance to the use of such a seemingly naive approach. But all of us know that it is the stories that move us and it is the stories that trap us. It is not data – but the story into which the data is woven that matters.

Stories reinforce the objective reality of our moral existence and yet they are plural, open and subject to multiple interpretation. Stories are human. This help us avoid the two extremes of empty relativism and scientific objectivism. Stories assert our moral value and equal status. Our equality cannot be measured – but it can be experienced in a respectful and well-told story about the life of a different human being.

Good stories have deep roots – bad stories rip up the roots and leave us lost and unable to make sense of the world.

John O'Brien and Simon Duffy

Introduction

The market in social and health care is dominated by 'for profit' organisations that tend to employ the least qualified staff to keep costs down (Jackson, 2011). "Winterbourne View" was one such private for profit care home owned by the large care provider Castlebeck, where abuse of adults with intellectual disabilities was filmed by a BBC undercover reporter. The men and women at Winterbourne View were physically and psychologically abused by those employed to support them. The Care Quality Commission (CQC) the independent regulator of health and social care in England has recently completed inspections of 150 services and has concluded that 50% are not achieving minimum baseline requirements.

Poor practice, abuse and scandals have become part of the history of services for people with intellectual disabilities. A usual response to a major scandal is a change in policy. Policies however have not been successful at changing human behaviours. Policies about services and support for people with learning disabilities reflect the basics of what a society considers to be the right thing to do.

We know what we should do to enable persons with intellectual disabilities to enjoy rich, interesting and inclusive lives as citizens, yet somehow we are still struggling to find the practices that can deliver what we already know we should do. Because we fail to deliver the good life for the majority of people, we continually formulate new policies, design new service systems, propose new (or re-branded) technologies and procedures. None of these deliver their promises for enough people for us to be satisfied. Why should this be so?

We know that it is people who can make the difference to the lives of vulnerable people. However, we are not sure who those people are. We need to know more about the people who have the ability and talent to take the actions that make a positive difference for people with intellectual disabilities. There are many talented workers who engage in participatory actions with men and women with intellectual disabilities, however not every worker has the talent to engage in empowering actions with the people they serve. We do know that some of the people share the vision and have cultivated the actions and reflection to develop practices that do enable people to live the good life. Kendrick (2004, p.8) refers to these workers as "people who have cultivated in themselves the capacity to enable the person to remain at the centre of all thinking." Who are these people? What are the attributes of these workers that should inform their recruitment in services for people with intellectual disabilities?

One of the attributes of these people is a capacity to develop appropriate relationships with people who experience intellectual disabilities. Relationships occupy an important and primary position in human life. We are born in and into relationships, our lives begin with relationships. We understand ourselves, our identities in the context of our relationships with others (Burkitt, 1991; Mead, 1934). Each of us can be a context for the other in a relationship. We also understand our relationships in the context of our identity, where some relationships have more power to shape identity than others. Do our relationships with persons with intellectual disabilities have this power?

...in one way or another, everyone relies on others, including the kindness of strangers, for his or her own survival and well-being.
[Sampson, 2003, pp. 147]

Wellbeing and Relationship

At it simplest, wellbeing is the same as happiness. Being happy is not just something to do with wealth, people with lots of money are not necessarily happier that people with less money. In most western countries, people are richer than they were in the past and yet the level of wellbeing has stayed the same. We are all engaged in the search for personal wellbeing. Each of us seeks a life that is 'enjoyable, meaningful, engaging and fulfilling' (Diener and Seligman, 2004, p. 2). We do not know of any policy about people with intellectual disabilities that have enjoyment, meaningfulness, engagement and fulfilment as goals.

An essential component of a person's wellbeing is the quality of her/his social relationships. People need social relationships that are supportive and positive to create a sense of belonging which sustains wellbeing (Seligman, 2002). We have a strong need to belong, to experience close long-term relationships and wellbeing depends on this need being met (Baumeister & Leary, 1995). There is a degree of circularity about the association between wellbeing and positive relationships in that people who experience a high degree of wellbeing also develop positive relationships with others (Diener & Seligman, 2002).

The absence of social relationships is associated with lower personal wellbeing. People with intellectual disabilities do have wellbeing experiences that are in the same range as the general population (McGillivray, Lau, Cummins & Davey 2009). However Lucas-Carrasco & Salvador-Carulla, (2012) found that people with intellectual disabilities who expressed dissatisfaction with work

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and with relationships also experience below average score of life satisfaction. Exclusion from social groups, even relatively trivial groups, can lead to strong negative feelings and distress (Barden, Gaber, Leiman, Ford & Masters, 1985; Williams, 2001).

The point of all this is that there is ample evidence to demonstrate that positive social relationships are good for peoples' wellbeing and the absence of friendships and relationships can undermine their sense of wellbeing. If we are going to be concerned about enabling those people with intellectual disabilities who rely on us to experience this sense of wellbeing, we are also going to have to renew our efforts to connect people to networks of social relationships.

Wellbeing, social capital and relationship

The person is the core of her community. Community for all of us is the people we interact with; many of our roles are defined by these interactions, and the places where these interactions take place. We cannot talk of community without implying relationships. The person who experiences intellectual disabilities is also the centre of her community and if she is not engaged in positive identity creating interactions in a variety of places with other people, then we have not been successful in building community around the person. We have to find and build community, rather than wait for it to come to us.

We have to seek out how to increase the participation of people who have been socially excluded. It is this social exclusion itself that constitutes the person's major disablement. This is the lesson from the social model of disability (Oliver, 1990). The trust, respect; the social justice that enables people in a community to act together, and are central to inclusion, are not often available to people with intellectual disabilities. This is unacceptable. The discourses that deny people trust, respect, and justice serve the

purpose of maintaining the powers of those who benefit from social arrangements that maintain social exclusion.

The story told by some who seek to maintain the social exclusion of disabled person is that community is hostile to disabled people. The person with an intellectual disability has to be supported to combat this hostility. However the rhetoric of refuge and protection do not hold, as this version of events does not serve the best interests of either the community or the person with intellectual disabilities. The purpose of this version of events is to deny the person a stake in the social capital that exists in her community. It perpetuates the myth that men and women with intellectual disabilities have little to offer their communities. Social capital "refers to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them" (Putnam, 2000, p. 19). To build social capital requires that we establish and nourish a sense of connection with members of the community.

When we observe that practices like Person Centred Planning do not deliver good, desirable and hopeful futures, it is very likely that the social capital – the reciprocity, trustworthiness and sense of connection between those who receive support and those offering it – is missing. When the pathological gaze of Person Centred Planning do not include the person's life enjoyment, meaningfulness, fulfilment, and engagement it has not been guided by what we hold in common as humans.

Methods and procedures are useful but they can not put the spirit of trust, connectedness, and justice into a relationship. You could have a lot of people engaged in your life, but if these people do not dignify you, do not believe that you are capable of living a better life, do not believe that you can learn, that you deserve a better life, are not full of hope about your future and so on, then the most important aspect of your social capital is missing. Thus social capital is not just about social networks; it is also the emotional connectedness of people who will walk with you, talk with you, who will champion your cause as if it is their own.

Social capital is accrued when there are mutual obligations and expectations on the part of people in a community. A person with intellectual disabilities cannot build up such obligations until she

is actually engaged in her community. If she is not included in this network of obligations, it is often because we fail to see that she has gifts to share with others. "In general, social capital functions through enabling people to engage with each other effectively by building trust, networks and cooperation" (Print & Coleman, 2003, p. 125).

Disabled people need social bonds in committed relationships, not just social interactions with strangers. We have to think of ways to stop service systems that make them strangers in our communities. We do this by connecting the person with people who are already well connected to their communities. Gretz (1992, p.12) refers to these people as 'community bridge builders'. A community bridge builder is someone who is not involved with human services but who is well known and respected in his or her community, he or she also belongs to many associations or groups. Community bridge builders are people who can then share their social bonds with those at risk of isolation and exclusion. It is impossible to think that we can get the people who depend on our help to be connected to their communities without the engagement of community bridge builders. This is not fanciful speculation, these people exist. How are we to find these people in our communities? It is possible that we do not seek to connect people with intellectual disabilities to community bridge builders because we do not think that the person has anything to offer in such relationships. This is a form of oppression. Not to believe in peoples' gifts is a form of oppression.

There are two competing worlds of caring, one based on formal human service systems and their bureaucracies and the other based in ordinary, informal ways of human relationships (Schwartz, 1997). Facilities, programmes and care plans do not in themselves make for community inclusion of persons who experience intellectual disabilities. People with intellectual disabilities need places to live, places to work, places for leisure and practices that enhance their wellbeing, their competencies as well as their relationships.

Relationships and place

The disabled person, just like any other citizen, does the business of citizenship by engaging in public discourses in public places such as community centres, work places, learning places, leisure places (Glover 2004). Oldenburg (2000) distinguishes between three kinds of places that are significant to the person and to community. The first places are our homes where we are connected to people by kinship, friendships and companionship. The second places are where we work. Third places are the locations where we undertake our leisure, learning and the exchange of goods and services, meet people, get to be known to others. It is in the third places that we are likely to find community bridge builders. These are places like the corner café, the local shop, clubs, places where we worship and so on. In each of these places we exert influence and are influenced by others. Thus one of the practices of citizenship is one of being influenced and influencing others. This is the same for the conduct of relationships.

Our biographies are often related to places. We have rich material on which to create the stories of our life when we have an abundance of these places. We were all conceived somewhere, born somewhere, grew up somewhere, we took our first step somewhere, went to our first school somewhere and so on. One of the great ills of the congregated and segregated total institution (Goffman, 1961) was that people only had one place to live their lives. We know how total institutions manufactured exclusion however we are less aware of the social exclusion in the places that people currently live in. That is, people have homes in the community, but they do not have any influence there. In this new kind of exclusion people are visible in their locality but they do not belong, that is they do not exert any influence in any of the three kinds of places identified by Oldenburg (2000).

Community exists for the person when at least some of the people he or she relates to are also co-users of the other places that they frequent. We start to build community when, for example, we

begin to engage with people in new roles, when the person we meet at work becomes a friend with whom we also occasionally share a meal in our home. We do these things naturally for ourselves. How are we going to enable people labelled as learning disabled to turn their encounters in places of leisure, learning, work or worship into relationships of influence? For too many persons with intellectual disabilities, community has been reduced to day programme, workshops, education programme, cooking programme, recreation programme and so on.

The next section we extend the ideas explored above by examining how service cultures either empower or disable people. Service cultures are both the products and producers of the relationship of workers to persons who experience intellectual disabilities; aspects of which include how hopeful they are about people's capacity to learn and benefit from their actions.

Two Dimensions and Four Service Cultures

If men define situations as real, they are real in their consequences.
[Thomas, 1923]

Earlier we asked the question: Who are the "people who have cultivated in themselves the capacity to enable the person to remain at the centre of all thinking?" The assumption being that these are the people who can factor in relationship, community, citizenship and inclusion in their actions with people with intellectual disabilities.

We theorise here about how we might start to think about service cultures and the people who create these cultures. We will be presenting this idea as both an attribute of the individual worker and as an attribute of the collective of individuals that makes up the service culture. The first of these two independent dimensions is the nature of the relationship that the supporter develops with the person he or she supports. This can be a relationship somewhere along the two poles of acceptance and rejection. The second dimension refers to the degree of hope or optimism the worker/supporter has about the person's capacity to benefit from his or her actions. The two poles here are optimism or hope and pessimism or hopelessness.

The idea about how the juxtaposition of optimism–pessimism and acceptance–rejection might influence workers actions and beliefs was originally proposed by Brown (1994). Brown's idea is developed further here. We consider these two dimensions, relationship and hope/optimism, to be independent of each other. When taken together they delineate four distinct possibilities about the process and outcomes of services to an individual and

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to the culture of the service. We refer to these four cultures as: Empowerment, Protection, Control and Punishment.

Dimension 1 – relationship

A supporter's relationship with a person with an intellectual disability can be thought of as existing somewhere along two extremes, with acceptance of the other person at one end and the rejection of the person at the other end. Acceptance and rejection are considered binary opposites. Both are possibilities in the way that we relate to another person. Furthermore, when we seek to accept a person, we also tacitly agree that he or she is at risk of being rejected. Our capacity for acceptance is simply the reverse of our capacity for rejection.

Acceptance ◀━━━━━━━━━━━━━━━━━━▶ Rejection

Figure 1. Two opposing poles of relationship

Whilst there is ample evidence to conclude that persons with disabilities are cast in deviant roles, it should not be taken for granted that all relationships between non-disabled and disabled persons are characterised by rejection (Bogdan & Taylor, 1989; Taylor & Bogdan, 1989). Bogdan and Taylor (1989, pp.137) describe an " 'accepting relationship' between a non-disabled person and a person with severe disabilities as 'one that is long standing and characterised by closeness and affection."

   Thus whilst some people are capable of accepting persons with severe disabilities, others are actively engaged in their rejection. It would be too simplistic to assume that everybody who is employed to support persons who experience learning disabilities is also engaged in 'accepting relationships' with them, although we may well wish this to be so. In the context of education, Cook (2004, pp. 308) points out that there is a strong body of

research since the early seventies concerning teachers' "formation of attachment, concern, indifference, or rejection attitudes towards students influences student's educational experiences and opportunities."

Each person's relationship with a disabled other is somewhere along these two poles of acceptance-rejection. We would wish that this is located towards the acceptance rather than the rejection half of these two poles. However in several recent studies, Cook and his colleagues have demonstrated that in inclusive classes, students with disabilities are over represented among teachers' attitudes of concern, indifference and rejection and underrepresented in their expression of attachment attitude (Cook, 2004; 2001; Cook, Tankersley, Cook and Landrum, 2000).

We associate the concept of acceptance with other similar concepts that define our relationships such as love, respect, liking, enjoyment in the presence of the other person, commitments to the other person, and attachment. Each of these ideas also has it binary opposite, matched with rejection such as love-hate, respect-disrespect, liking-disliking, enjoyment-sorrow, commitment-indifference, and attachment-detachment.

Our relationship with each person can be thought of as existing somewhere along these two extremes. Whilst we are all capable of hate, dislike, disrespect, distance and indifference, this is not often our experience of people. However, these are often characteristics of our relationship with those who get to be seen as the 'other'. Some current examples of people cast as others are: Refugees, asylum seekers, economic migrants, 'welfare scroungers', the mad, the bad and the outrageous. The 'other' is often the focus of scrutiny. What are the policies, the practices and service cultures that are part of the production of 'otherness'?

Dimension 2 – hope/optimism

Having a sense of optimism and hopefulness about one's life sustains our actions during difficult life episodes (Snyder, Harris, Anderson et al, 1991, Braithwaite, 2004). Psychologists refer to this as a state of efficacy (Bandura, 1982; Zimmerman & Rappaport, 1988). Efficacy is about a sense of purpose for taking action. The basic idea of self-efficacy is that the person thinks that it is worth his or her while to take action to address an issue or a problem and that the action taken will lead to desirable outcomes.

Snyder et al (1991) identified two aspects to hope: Goal and Agency. Goal refers to desirable outcomes and agency is concerned with optimism about the result of one's action. The person who experiences low self-efficacy is likely to say: 'What's the point of doing…we have done it all before…nothing will change.'

It is bad news for people with intellectual disabilities when the people who support them think that there is little point in providing them with new opportunities. We can think about this dimension of hopefulness as also existing along two opposite poles, with Hopefulness and Optimism at one end and Hopelessness and Pessimism at the other end.

Hopefulness or Optimism ⟷ Hopelessness or Pessimism
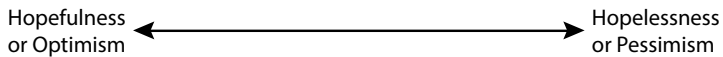
Figure 2. The two opposing poles of hopefulness/optimism and hopelessness/pessimism

Hope also refers to a concern about the future, to events that have not yet occurred. Hope contributes to our planning to meet goals, which necessarily involves a willingness to take action rather than waiting for the hoped for event to happen by itself.

In a review of the literature, Nunn (1996) identified the following four attributes of the hopeful person:

1. He or she perceives a capacity for future personal development.
2. He or she has a purpose in life.
3. He or she anticipates the support of others.
4. He or she has a high self-esteem.

We contend that services for people with intellectual disabilities should seek out workers with these attributes.

Four service cultures

Figure 3 shows the juxtaposition of the two dimensions, relationship and hope. This combination provides four theoretical possibilities about how a worker might behave and how we might define a service culture.
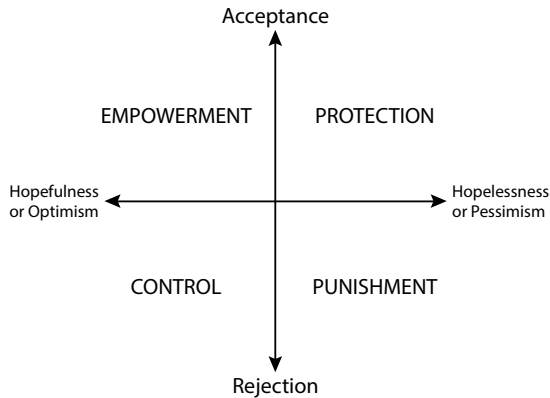
Figure 3. Four possible service cultures that can arise from acceptance/rejection and optimism/pessimism

The four possible combinations are:

1. Rejection of the Person and Pessimism/Hopelessness about his/her capacity to learn/benefit from one's actions.
2. Rejection of the Person and Optimism/Hopefulness about his/her capacity to learn/benefit from one's actions.
3. Acceptance of the Person and Pessimism/Hopelessness about his/her capacity to learn/benefit from one's actions.
4. Acceptance of the Person and Optimism/Hopefulness about his/her capacity to learn/benefit from one's actions.

Punishment: high rejection & high hopelessness/ pessimism

This combination of rejection and hopelessness/pessimism is likely to lead to a service system that is characterised by punishment. This is in fact the defining characteristic of the now discredited institutional model of services that has been associated the abuse and neglect of people in several countries. And the model witnessed at Winterbourne View.

It is a least a theoretical possibility that some of the people currently employed in services for persons who experience learning difficulties are likely to be towards the rejection-pessimism ends of the model. It is possible that a worker's model might change from one person to another, that is the degree of acceptance-rejection and optimism-pessimism is person dependent. What we know for certain is that we cannot continue to employ anybody whose relationship with any person with intellectual disabilities is characterised by rejection. We further suggest that the person who is not hopeful about his or her own future is unlikely to be hopeful about the future for anybody else, especially the future of any one that he or she rejects. A culture of punishment is also likely to be against the social inclusion of persons who experience learning difficulties and consequently it supports their segregation.

Control: high rejection & high hopefulness/optimism

In this system, people believe that with efforts and resources persons with intellectual disabilities could lead better lives and would benefit from opportunities. However because these people are also rejecting of the person, they do not think that she is deserving of either their efforts or of society's resources. In such a system, the culture is one of control. Here the person is often under surveillance. Being rejected also leads to negative emotions which can be injurious to the wellbeing of the rejected person. It is also likely that the rejected person incorporates a sense of worthlessness in his or her understanding of his or her identity. Systems that are primarily about control are also likely to employ workers who share this belief about people who experience learning difficulties. One indicator of a service that is about control is likely to be the production of stories of the person as troublesome (Nunkoosing & Haydon-Laurelut, 2011; Nunkoosing & Haydon-Laurelut, 2012).

A characteristic of the Control model is that it believes in a constant engagement of training and treatment for people who experience learning difficulties until they can become eligible for living along side us in the midst of our communal lives. Control is easier when people are segregated. We do not need to treat or control people as we set up conditions that maximise possibilities for people to meet, live, learn and share together (Evans & Meyer, 2001).

Protection: high acceptance and high hopelessness/pessimism

Here people are accepted and loved but the cultural belief is that they are incapable of learning and of living inclusive, interdependent lives, of working and so on. It is often the case that a protective culture is based on the stories that society is hostile to people who experience learning difficulties and therefore it is better for them to avoid interaction with the communities. This may then become an excuse for a congregate model of services and of exclusion. It is inevitable that 'victim blaming' is an aspect of this culture (Blyth & Milner, 1994).

It is also likely that acceptance is from people who are related to the disabled persons, but who also think that their relatives need to

be protected from society. Furthermore they would feel safer and more secure about the future if they know that the relative has a permanent home where he or she is loved and cared for.

The acceptance leads to real care, concern and love for the disabled person but when matched with a sense of hopelessness and pessimism, it becomes difficult to see a different possibility, such as one where the person is seen as capable of learning, and of developing her own identity and strength, of participating in all aspects of an ordinary life. Here protection is not benign; it serves to deny the disabled person a more desirable future.

Empowerment: high acceptance and high hopefulness/optimism

Empowerment in this context values collaboration and relationship building between the disabled person and his or her supporters. In this collaboration, there is understanding of the potential for people, ideas and things to exert both beneficial and harmful effects for the persons with the least power in the relationship. This relationship is based on hopefulness and optimism about the partner's capacity to benefit from opportunities to increase his or her wellbeing and quality of life.

The products of this empowering association are:

1. The promotion of wellbeing.
2. The flourishing of relationships and community connectedness.
3. Hopefulness about the person's future.
4. Participation in the creation of ever changing new stories.
5. The elimination of unwholesome and unjustifiable dependency.

Service cultures with the potential to punish, control or protect also have the potential to oppress people who experience learning difficulties. Oppressors do not liberate people; people liberate themselves when the people, ideas and things stop oppressing them. Liberation is empowerment. How are we to define our relationship with the people, ideas and things that oppress people who experience learning difficulties?

Empowerment requires that there is a redistribution of power to enable persons who have been excluded from political, economic and life enhancing processes to overcome such exclusions and become part of that process (Arnestine, 1969). The model we present suggests that we have to believe that we can support men and women with intellectual disabilities to engage in this process of liberation and our vision of social inclusion incorporates peoples' active engagement in the political, economic, social and life enhancing processes of their neighbourhoods and communities.

In the context of the model presented here, we define empowerment as:

A person's enjoyment of a high degree of personal influence and choices from a wide range of options and his or her social engagements at home, work, leisure, worship and other places to enhance his or her sense of wellbeing as a result of being connected to and supported by a network of social bonds in committed and accepting and hopeful relationships.

Empowerment and Narratives

Some stories enhance life;
others degrade it.
So we must be careful
about the stories we tell,
about the ways we define
ourselves and other people.
[Burton Blatt, 1987 cited in O'Brien and Mount, 1191, p.89]

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The realities of our lives are constructed in relationships by means of language to create meanings. These experiences of our lives are organised and made real by means of stories.

We can have many different stories about the same events. The problem for us is that these different ways of rendering accounts are likely to evoke different meanings and thus call for different actions. To an extent, the four cultures of services delineated above are themselves different possible accounts of the lives of people who experience learning difficulties. All four of these accounts of intellectual disability exist in our wider culture and in the culture of services.

Stories are powerful because they shape our meanings and experiences; they contribute, by means of language, to cultures. The people who share a culture also share its language and its perspective about the world. Whilst drawing from the common language of English, the discourses of empowerment, protection, punishment and control are going to be dissimilar.

To deny people their stories is to deny them their very existence. Stories of empowerment, community, and relationships about the lives of persons who experience learning difficulties can be read as stories of resistance. these new stories of triumphs over

the oppressive stories of control, punishment and protection build up dialogues to counter the monologues of 'disablement' (Fergusson & Fergusson, 1995). These stories give us hope as they provide us with evidence that there are alternative world views where disability is only one element of a person's life and this one element has to be put in its proper place rather than being allowed to become life defining as it does in the disablist discourses of some.

Stories are lived as well as told. The things we do make us who we are and who we will become. Stories are always constructed in time, in place and in history. These stories are empowering because they deliberately seek to move away from a deficit model of disability, that impedes wellbeing, to a strength perspective (Saleeby, 1992) that celebrates difference and give voices to stories of human endeavour that have been suppressed. The idea of 'ability' runs counter to the disablist master narrative of intellectual disability. These stories of ability empower people and their supporters. The disablist master narratives have colonised the lives of both persons with intellectual disabilities and their supporters with their professional ideas, language and 'expert' knowledge which can maintain 'disempowerment' as it seeks to eliminate other forms of knowing in the community.

Our challenge is to seek more opportunities to live in these new empowering stories so that we can build a mass movement to create new narratives of people with the label intellectual disability and their supporters, and their lives in communities. We have to be careful about how we tell our stories in this struggle rather than give in to our tendency to appropriate the stories of the lives of people who experience learning difficulties. If we do that we will maintain the colonisation of peoples' lives. Rappaport (1995) points out that socially disadvantaged people have their stories written by others and that these stories are often negative, narrow and thin.

When people tell their stories, they input into communal narratives which constitute the alternative meaning and knowledge making that help us to find ways to include people. We have to seek out the places where people can go to create, develop and sustain new identities. Where these places do not exist, we have

to create them in participation with people with intellectual disabilities and with their supporters. Narratives are not just words written on pages. Pictures, performances, conferences and rituals also make up the narrative of a community. What we do together in relationships is our community narrative. What are we going to do with people with intellectual disabilities to create a new community narrative of their triumph?

Because people are using different discourses to create their world, we essentially have a clash of cultures. One culture that values acceptance and hopefulness and one that is rejecting and pessimistic about people with intellectual disabilities. These are cultural conflicts because the two groups draw on different discourses to create their worlds. One culture seeks to present the strength and gifts of people labelled as intellectually disabled; the other finds this to be an unrealistic and fanciful notion. It is probably a mistake to think of these as two distinct cultures, rather we exist somewhere along a continuum and these two forms of thinking about intellectual disabilities and people who experience intellectual disabilities are constantly interacting.

Below we suggest how the four different service cultures might story an aspect of a person's life:

Empowerment:

"Mr. A is man with a supportive family who visit and like to know what is going on in their son's, brother's, nephew's life. This network of relationships is an asset that will need to be supported and encouraged to increase its involvement in this man's life. There is also the need to seek ways to increase his opportunities for self advocacy and to extend his relationship network."

Protection:

"Mr A's contact is currently restricted to his carers and the occasional family visits. As Mr A's parents get older they are likely to visit less and less and this is likely to be upsetting for him. He might be able to get a volunteer or citizen advocate to take him out occasionally. He has many friends here amongst the staff and residents"

Control:

"As Mr A gets older he will have to learn to rely less and less on his families. They find it difficult to visit him as it is and have already reduced the frequency of their visits. His key worker will then become his main advocate; we have a policy to change the Key Worker every six months to prevent too much upset when staff leave."

Punishment:

"Mr A's does not appreciate the visits from his elderly parents. It is difficult to know what he gets from these rare visits as he does not seem to remember who they are. It is for the best that they stop disrupting his routine by these visits."

In the very small exemplars above we see how the Protection, Control and Punishment narratives are problem saturated. These snippets of stories are familiar to people in formal human services. Most of these versions of the same event are not empowering. We recognise them as possible stories because these different versions of events are part of our own cultural lives.

Seligman (2002) identified three components of wellbeing as the pleasant life of positive emotions and mood; the good life of engagement, enjoyment, meaningfulness and fulfilment and the meaningful life where there is a meaning to life, a sense of hope and a concern about the future. It is our purpose to seek the pleasant life, the good life and the meaningful life for people with intellectual disabilities. These aspects of wellbeing should also become the basis for our stories together.

Our stories should take care to understand that:

1. Problems are constructed in specific contexts that produce their current meanings. We can tell different stories in different contexts and consequently change the problem saturated stories of disability that contribute to the oppression of people.
2. The stories we tell about our work send messages about people with intellectual disabilities and their supporters.

3. We can either invite the enactment of life constraining or of empowering stories. Stories have the potential to allow us to become observers of our actions and interactions with people with intellectual disabilities.

4. An empowerment perspective stresses that the solutions to an individual's problems will be unique and linked to his or her environments. We have to pay careful attention about who we invite to engage in the lives of people with intellectual disabilities.

5. Stories stand against the attempts to seek universal interpretations of human experiences for these close down options to seek new stories.

We suggest a redefinition of the role of the service and support organizations. Rather than solely providing services and support, organizations serve as bridges between people and community supports. For this reason, the concepts and research findings associated with social capital contribute to a reformulation of organizational role.

Disability organizations, like other bridging organizations in the community, enhance social networks and social capital of all people. [Gardner and Carran, 2005, p. 172-173]

What Can Be Done?

Abuse of men and women with intellectual disabilities continues. Policies (of which there has been many since the scandals of the 1960s) have not changed this aspect of the intellectual disability story. Why?

Policies have concentrated on inclusion, health and social care and responsibility for its delivery and so on. However policies have not and perhaps cannot, sanitise the stigma of intellectual disability and end the production of disablism. They can however acknowledge their part in these processes and seek to create spaces of resistance.

Whether we foster cultures of empowerment, protection, control or punishment is everyone's responsibility.

What stories are created by the actions of policy makers, commissioners and local authorities? Consider the story created by an out-of-area placement. It is certainly one of banishment and possibly of punishment. The person arrives with a story that he or she is to be controlled or punished. The actions of policy makers, commissioners and services influence the social identities of people with intellectual disabilities and hence staff-person relationships that are inextricably linked to these. Commissioning of residential provision, particularly out-of-area placements where people are separated from local community and family, must end.

   At the level of the organisation, the 'for profit' organisation creates a story of people with intellectual disabilities as consumers. However this is very often just a gloss, given the lack of agency afforded to persons with disabilities. Underneath that story is another, where the person becomes a commodity. The construction of stories of people with intellectual disabilities as commodities is unlikely to support the creation of a culture leading to their empowerment and rather creates cultures of protection or control where they are 'managed'. When persons with intellectual disabilities are no longer profitable commodities

capital will move on, as it does when services close for commercial considerations which are divorced from the lives of those who 'use' their services. They may also face punishment if they do not respond appropriately to this management and this may be constructed as challenging behaviour (Nunkoosing and Haydon-Laurelut, 2011; Nunkoosing and Haydon-Laurelut, 2012).

The message for policy makers is that regardless of the quality of the services, the stories that are created by such services treat people with intellectual disabilities primarily as financial investments.

Reflection on specialist services

Policy makers, commissioners, service providers, health and social care professionals as well as individual staff should pay attention to the impact of their actions on the construction of cultures. Services specifically commissioned for persons with labels such as Challenging Behaviour or Autistic Spectrum Disorders, for example, tell stories and create cultures that tell of pathological 'service users'. Whatever the rationale for such services they are unlikely to create empowering stories of people with intellectual disabilities. After decades of research in intellectual disabilities it is not tenable to be neutral or to wait for the 'evidence' to come in.

Systems based evaluation

Policy makers, commissioners and regulators need to widen the focus of their evaluations to encompass the system of service provision (Schalock, Verdugo and Gomez, 2011). Traditional evaluation of individual services or 'parts' is unable to account for such phenomena as it will not seek to understand how the system of care operates as an emergent whole and whether it is productive of empowering, controlling, punishing or protecting outcomes. Evaluations that take seriously the systemic nature of lives will seek to understand what kinds of social worlds are being made in the actions of services (Pearce, 1994).

Staff training: relationships and social construction

Staff training has tended to focus on instrumental, technical competencies of staff (Jackson, 2011) and there is a need to include a focus on the relational aspects of the human work of caring for and supporting others. This should include the development of hopefulness and accepting relationships with those they serve. Commissioners and inspectors of services should seek to ensure that staff in services are focused on issues of staff-person relationship and that there is a basic awareness of the history of intellectual disability and intellectual disability work, highlighting the social constructions of disability; the stories our culture has told and still tells about people with disability and the roles of staff in persons lives. Staff and services should be able to demonstrate an ability to recognise different service cultures, foster empowering cultures and address the risk of straying into the values and practices of punishment, control and protection.

In order to change stories of intellectual disabilities we need to change the stories our work tells about them and about us.

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This publication is for an international audience and therefore it uses the most commonly used terms to refer to specific groups of people.

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The Need for Roots Series

The Need for Roots is a series of publications from The Centre for Welfare Reform which explores the purposes, values and principles that ground and nourish the changes in relationship, practice and policy necessary to creatively support full citizenship for all people. Our aim is to foster the sort of inquiry that will lead to a deeper understanding of core words like person, community, citizenship, justice, rights and service, as well as newer terms emerging from efforts to reform social policy such as inclusion, self-direction and personalisation. Proceeding as if the meaning of these key words is obvious risks them becoming hollow and spineless, functioning as rhetorical filler or tools of propaganda and fit only for reports and mission statements.

THE NEED FOR ROOTS

We have named the series after the title of the English translation of a book by Simone Weil, a philosopher and activist. She wrote in 1943, at the request of the Free French Resistance, to chart a way her native France could renew itself and its citizens after victory over the Nazis. Far more than her specific conclusions we admire her willingness to search deeply in history for the distinctive strengths of her people and their communities, to think in a disciplined and critical way about human obligations and rights and the conditions necessary for their expression, and to risk mapping out in detail how her ideas might be realized in practice (a meaningful effort even though few if any of these specific recommendations were judged practical enough to attempt). As well, we are awed by her courage, throughout her short life, to struggle to live in a way that coherently expressed her beliefs and the insights generated by that effort.

We offer this series because we think it timely. Real progress reveals powerful ways that people at risk of social exclusion, because they need some extra help, can contribute to our common life in important ways. But there are substantial threats to sustaining and broadening this progress to include more people.

We want this series to benefit from the experience of all disabled people, of people who require additional support as they grow old, of people in recovery from mental ill health and trauma. We invite them to consider this series as a way to speak for themselves. In describing its social context we will speak from our experience of the people who have taught us the most, people with learning difficulties and other developmental disabilities, their families and allies.

In the span of two generations the life chances of people with learning difficulties and other developmental disabilities have markedly improved. Family organising and advocacy have redefined private troubles as public issues

and attracted political support and rising public investment in services. The growing cultural and political influence of the disabled people's movement has established the social model of disability as a corrective to an individualistic medical model, declared the collective and individual right to be heard and determine one's own life course and the direction of public policy, and struggled with increasing success for the access and adjustments that open the way to meaningful civic and economic roles. People with learning difficulties have found allies and organised to make their own voices heard, increasingly in concert with the disabled people's movement. Discrimination on the basis of disability is illegal in more and more jurisdictions and the UN Convention on the Rights of Persons with Disabilities asserts the right to full citizenship and the assistance necessary to exercise that citizenship. The population confined in publicly operated institutions has fallen dramatically and institutions in any form are losing legitimacy. Social innovators have created effective practices and approaches that assist people to develop their capacities, exercise meaningful direction of their own lives, and participate fully in their communities. More and more people with learning difficulties enjoy life in their own homes with chosen friends or partners, are employed in good jobs, join in civic life, and use generally available public services and benefits.

These improvements in life chances merit celebration, but the journey to citizenship for all is far from over. Governments' responses to fiscal crises have cut public expenditures in ways that fall disproportionately and harshly on disabled people and their families. Scandalous mistreatment, hate crime, neglect, and abuse continue to plague everyday life for far too many disabled people. People whose impairments call for assistance that is thoughtfully designed and offered in a sustained way by trustworthy, capable, committed people are particularly vulnerable to exclusion and deprivation of opportunity. The thrust to self-direction is blunted by rationing, restrictions on people's discretion, and risk management. Authorities turn aside people's claims on control of funding and family requests for inclusive school experiences for their children or entangle them in labyrinthine procedures. Far too few people with intellectual disabilities and their families hold the expectation of full citizenship and too many straightforward desires for access to work and a real home are trapped in bureaucratic activities adorned with progressive sounding labels; so rates of employment and household formation remain low.

There are even deeper shadows than those cast by inept or dishonorable implementation of good policies or clumsy bureaucracies nervous about scarcity and risk. Powerful as the social model of disability and the language of rights has been in shaping public discussion, individual-blaming and controlling practices thrive. Authorities typically moved from unquestioned control of disabled people's lives in the name of medical or professional prerogative to the unquestioned control of disabled people's lives in the name of a gift-model of

clienthood,which assigns authorities responsibility for certifying and disciplining those eligible for publicly funded assistance. As the numbers of people diagnosed with autism increases, more and more families organize to seek public investment in discovering or implementing cures. Most worrying, lives are at risk in the hands of medical professionals. Even in the area of appropriate medical competence, people with learning difficulties are at a disadvantage, experiencing a higher rate of premature death than the general population. The growing power of testing during pregnancy enables what many researchers and medical practitioners call "secondary prevention through therapeutic abortion," framed as an option that growing numbers of parents accept as a way to avoid what they imagine to be the burdens of life with a disabled person. Medical researchers seek even more ways detect and terminate disabling conditions. Some defences of euthanasia seem to assume that disability makes life an intolerable burden - despite all the evidence to the contrary.

An adequate response to the mixture of light and shadow that constitutes current reality has at least three parts. Two of these are more commonly practiced and the third is the focus of this series of publications. First, keep building on what works to develop, refine and broaden the practices necessary to support full citizenship. This will involve negotiating new boundaries and roles in ordinary economic and civil life and generating social innovations that offer people the capacities to life a live that they value. Second, intensify and sustain organizing and advocacy efforts: build activist groups; strengthen alliances; publicly name problems in ways that encourage positive action; agitate to assure adequate public investment, protect and improve positive policies and get rid of practices that support exclusion and unfair treatment; and educate to increase public awareness of the possibilities, gifts and rights of all disabled people. Recognize that both of these initiatives will need to be sustained for at least another generation and probably as long as humankind endures.

These two initiatives - building on what's working and organising for social change - have two advantages over the third. They both encourage immediate practical actions that concerned people can take today and don't demand making time for study and reflection. Neither questions a commonsense view of history as steady progress: we may suffer setbacks at the hands of today's opponents but our trajectory is upwards and we can act free of the backward ideas of the past. Our culture offers few resources for sober consideration of the shadows that haunt our efforts, the ways we are ensnared by history and enduring human potentials for indifference, tragedy and evil. So it is understandable that we take refuge in the idea that progress is inevitable if we are smart enough, indifference can be enlightened by proper marketing, and tragedy and evil disgarded as superstitions.

The third initiative, growing deeper roots, is a call for a different kind of action. *L'Enracinement*, the French title of Simon Weil's book, means something closer to "rooting" –actively putting down roots rather than just acknowledging that roots are needed. Deepening the roots of our work is a matter of conversation, with the words written down by the authors in this series, with one's self in reflection, with friends and colleagues in discussion, with a wider public in debate and political action. We hope that time spent in study will add meaning to our current efforts, foster a better understanding of challenges and possibilities, and generate and refine creative actions.

John O'Brien and Simon Duffy 2013

To find out more about The Need for Roots project visit The Centre for Welfare Reform's website.

Publishing information

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The Centre for Welfare Reform was established in 2009 to develop and help redesign the welfare state in order to promote citizenship, support families, strengthen communities and increase social justice. The Centre's fellowship includes a wide-range of social innovators and local leaders.
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