



Leadership for social inclusion in the lives of people with disabilities

Jane Sherwin
Consultant, New Zealand

Abstract

While there is widespread espousal that social inclusion is important in the lives of people with disabilities¹, significant progress is yet to occur. This article identifies five challenges for those in leadership roles: developing a deep sense of what the concept 'social inclusion' really means; confronting the values questions; developing consciousness of what the community is taught through the actions of services; transforming the role of services and workers; and the use of theory-based knowledge. The article also explores the attributes of those in leadership roles, so that they are more equipped to respond to these challenges: ethical and moral leadership; a combination of conceptual clarity, insight, knowledge and wisdom; authentic relationships with people with disabilities and family members; an appreciation of history; and a faith and efforts in things that are likely to bring dividends.

Key words

Social inclusion; disability; socially valued roles; leadership; marginalised groups.

People with disabilities across the world and throughout history have experienced rejection, separation from ordinary life and relationships, powerlessness within service systems, loneliness and isolation. It is no surprise then that social inclusion is sought after. Yet social inclusion continues to be aspirational for many people with disabilities, with little authentic and sustained progress having been made in this area. This, then, is an ethical and practice issue for those people in leadership roles whose responsibilities include being visionary, influencing others and enacting change in communities and service systems.

This article critically explores notions of social exclusion and inclusion, and then

applies the lessons from this to the challenges facing people with disabilities and leaders.

What the non-disability literature says about social inclusion and exclusion

Most of the literature defines 'social inclusion' by its apparent opposite, 'social exclusion'. Buckmaster and Thomas (2009) and Hayes and colleagues (2008) describe how the term 'social exclusion' gained popularity in France in the 1900s, and referred to those people who were excluded from social support. This was a poignant issue in France because of the values held around social solidarity and the assumption that the State has a central role in promoting

social cohesion. In more recent years, the European Union (EU) has also held an agenda regarding social exclusion. Unlike France's position, the EU focus has been on employment and sustaining benefit systems (Buckmaster & Thomas, 2009; Hayes *et al.*, 2008).

There are a range of views about the cause and therefore the definition of social exclusion. Consistent with the history in France, there is one position that social exclusion is the breakdown in bonds between the individual and society (Buckmaster & Thomas, 2009). This definition is related to others that highlight structural problems within the system, such as the interplay between problems of unemployment, limited education, low income, poor housing, poor health and family breakdown.

An alternative view is that individuals experience social exclusion because of poor choices that they have made. Vinson (2009) highlights this interpretation in his exploration of the experience of the multi-generationally disadvantaged. He identifies the view of many in our society that people become socialised to become dependent on welfare, become unconscious to the stigma of receiving welfare and so choose to remain socially excluded. Encompassed in this view is that young people lack role models who demonstrate the benefits of employment and social participation. These standpoints clearly ignore the structural barriers that contribute to social exclusion.

Buckmaster and Thomas (2009) conclude that most definitions of social exclusion referred to a lack of opportunity to participate in social, economic and/or political life. They identify four criticisms of research, literature and social policies on social exclusion.

1. The definition of social exclusion is commonly linked to poverty, however they identify problems with this: an understanding of social exclusion as poverty leads to a focus on financial well-being, consumption and income adequacy, and ignore the other issues and factors in social exclusion. This view leads to solutions being primarily about employment, but does not address low pay or poor working conditions. In other words, this definition leads to an acceptance of

low pay and poor conditions so long as employment is achieved.

2. The term has limited scope. Social exclusion and inclusion are seen as having a binary relationship, so the solutions are seen to lie with 'getting people over the line' (of inclusion). Therefore, it is possible that people would be considered included if they are employed, even though they might still be below the poverty line with all of its associated impacts on health and social isolation.
3. Solutions are primarily top-down, whereby those who experience social exclusion have few active roles in determining the solutions.
4. The criterion to be considered socially included is acceptance of the dominant societal values and lifestyle, leading to moralistic judgements if individuals reject the dominant norms.

Thus, there are problems with the term social exclusion due to the lack of agreement about definitions and contentious (or incoherent) theoretical underpinnings. Even so, the reality of people's experiences cannot be denied.

The experience of people with disabilities

The importance of life in and as part of community for all people with disabilities underpins Article 19 of the *UN Convention on the Rights of People with Disabilities* (European Coalition for Community Living, 2009) and is supported by findings about the social exclusion of people with disabilities in reports such as those released by the National People with Disabilities and Carer Council in Australia (2009) and the Economic and Social Research Institute in Ireland (Gannon & Nolan, 2005). Reports such as these consistently describe the low levels of education, income and employment by people with disabilities. Emerson and Hatton (2007) also identify the link between disability, social exclusion and poorer health. Both reports also indicate limits in broader aspects of participation in the life of one's community and society. For example, the Irish report describes that people with disabilities are less likely to join a club, less

likely to talk to neighbours, and less likely to go out for entertainment. The Australian report also describes that still today many people with disabilities cannot access public facilities and are excluded from taken-for-granted life paths such as going to kindergarten and schools, followed by work, establishing one's own home, having holidays, marriage etc. Despite the closure of the majority of institutions where people were 'shut in', people with disabilities now find themselves 'shut out' (p1) from community life.

Three factors that contribute to the experience of social exclusion are the following.

1. *Societal beliefs and values*

One does not have to lift the fabric of our society very deeply to uncover deeply-held beliefs about people with disabilities. The experience of being perceived and treated as the 'other' is captured by Wolfensberger (in Race, 1999) when he describes 10 deviancy roles, also understood as stereotypes, that people with disabilities are likely to be cast into. These negative roles, such as 'eternal child', 'sick', 'menace', 'burden' and 'less than human' are expressions of rejecting the shared humanness of people with disabilities. They are not only deeply embedded in our society now, but in our history as well. These circumstances are highly likely to continue into the future as this 'othering' process is linked to our values, and people with disabilities embody many things that our western society negatively values: people with disabilities are perceived as unattractive, unproductive, dependent and taking away from the comfortable lives of others. Perceptions of people with disabilities as less worthy lead to people being treated as less worthy, and this plays out in both community life and in the service system.

2. *How service systems typically function*

A further set of struggles for people with disabilities, and often their families, relate to how our service systems typically operate. The dominant forms of service continue to be building-based and group-based, as evidenced by group homes, day centres and sheltered

workshops. While these may be located within community neighbourhoods, people are not connected to local community life or are only superficially present in community life such as visiting through local shops and parks. People with disabilities might have greater community presence than they did in the days of institutions on the outskirts of town, however the common patterns are that they lack participation in community life and lack the web of relationships that others take for granted. Lemay's 2007 literature review indicates that not only were the social networks of people with disabilities smaller than the networks of people without disabilities, but that those networks were composed primarily of other service recipients and paid staff, even though people were in community-based residential homes. Emerson (2005) notes that there is increasing rhetoric about social inclusion in that while much is talked about, little is delivered and that this will lead to a demand for 'services to deliver' (Emerson, 2005: 20).

3. *Identity needs and economic imperatives*

Further, the forces to keep people with disabilities in excluded states are many. These include tribalism (that humans define themselves by 'who they are not'; boundaries of who is 'in' are defined by who is determined as 'out'), and societal values such as individualism. In addition, many western economies now have a reliance on devalued groups: it is these groups who do the work that others with a valued status do not do, and it is they who are a source of employment (Kitchin, 1998; Race, 1999) for the many who work in what is frequently called the 'disability industry'.

What is desirable in the lives of people with disabilities, for which the term 'social inclusion' is commonly used

'We desire a place within the community! This place is not just somewhere to lay down our heads, but a place which brings comfort and

support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this great things may flourish.' (National People with Disabilities and Carer Council, 2009: viii)

This quote poignantly captures what is meant by the term 'social inclusion' and other terms such as 'community living', 'ordinary lives', 'typical lives' and 'lives rich with meaning'. There is occasional reluctance to consider that there could be a single notion of 'typical' or 'ordinary', which is understandable given the breadth of human characteristics and preferences. However, if consideration is given to typical lives relevant to gender, culture and age, then in, for example, Western society, adults generally hope to have a home, opportunities to contribute, a family or a small intimate group, a wider social network, things that give purpose, good health, having a say over the important things in life, safety, a belief system, opportunities to learn and develop one's skills and abilities, and to have one's contributions recognised (Wolfensberger *et al*, 1996).

Flynn and Aubry (1999) did an extensive review of the literature, including research literature, regarding integration and people with disabilities and found that Wolfensberger's definition was '*the richest and most useful*' (p296). Wolfensberger (1998) uses the term '*personal social integration and valued social participation*' and defines it '*as adaptive participation by a socially devalued person in a culturally normative quantity of contacts, interactions and relationships, with ordinary citizens, in typical activities, and in socially valued physical and social settings*' (p123). This definition assists with understanding that physical presence in community life is only one element and that the other elements are community participation and a range of relationships with people who have a valued status. If people are merely present in the community, then they do not experience social integration, according to this definition. A lack of a range of relationships means that people are likely to not experience belonging to a network of friends and acquaintances.

Challenges for leaders

As the broader literature on social exclusion indicates, the causes of social exclusion can reside either because of problems 'within' the

individual or because of structural barriers. With regard to the former view and people with disabilities, limits to social inclusion that are understood to be because of limited capacity in the individual are seen in efforts that have had a rehabilitation or training focus (for example, White *et al*, 2010). Responding to issues of social exclusion at a policy level and systems level frequently involves processes to identify the marginalised groups, consultation and facilitation of access to services, such as in a report by Brackertz and Mereduth (2008).

These efforts are largely insufficient to achieve the spirit of social inclusion described in the quote by the National People with Disabilities and Carer Council or the elements of social integration and valued participation as defined by Wolfensberger. Concerted efforts by leaders are necessary to face the challenges in a real way, alongside people with disabilities and even in the absence of positive policy or enabling systems. It is not sufficient to simply have more services involved in the lives of people with disabilities; what is important is what those services do, and what the leaders in our communities and services do.

Leaders could be found in the disability human service system, in people with disabilities themselves, in families and in communities. The struggle for social inclusion requires that those in leadership roles address the following five challenges.

1. Develop a deep sense of what the concept 'social inclusion' really means.

As identified earlier, the term 'social inclusion' is described as problematic in the broader literature since it is seen as the antithesis of social exclusion. This is also found to be problematic in the lives of people with disabilities.

Many who seek social inclusion in the lives of people with disabilities assume a common understanding about what this means and what the goals are; they commonly speak about 'ordinary lives' and community living. In practice, the term has been co-opted. This is seen in a not unusual example of a service that groups people with disabilities, takes them in a service-owned bus to a centre-based programme and refers to this as an inclusion programme because it is located in

the community. This practice is in contrast to a service that supports individuals to pursue ordinary activities with non-disabled citizens, which also refers to its programme as inclusion.

One result of this is that there are claims that people with disabilities are socially included, when it is clear that they are not. The overwhelming issue though is that a significant proportion of people with disabilities remain marginalised in our communities.

It is only if leaders have a sense that social inclusion refers to much more than community presence that we are on a path with potential. This requires an appreciation of the limits of the terms 'social exclusion' and 'social inclusion' and an appreciation of the breadth and depth of the term 'social inclusion', better captured in the definition of personal social integration and valued social participation by Wolfensberger.

Fundamentally, this is a challenge for 'imagining better' (Kendrick, 2002). Kendrick reminds us that imagining an alternative can assist the progress to another reality. Others have referred to this as dreaming or envisioning. This requires an orientation to people with disabilities that sees the good qualities, the capacities and the potential in each person. It requires a capacity to disengage from one's singular role as manager or worker or family member and to stand in the shoes of the vulnerable party and use this as a filter for all decisions effecting the vulnerable person. It is a task of leaders to awaken the sense of possibility in those around them, and to help shift the mindset from low expectations and the reliance on the traditional group and building-based responses. Needs can be understood not as barriers to participation, but rather as clues to those conditions that are more likely to bring out the best in each person. Wishes for a better, more inclusive and participative life can be seen not as a futile expression of the person's self-delusion, but rather as something to be taken seriously.

This requires leaders in services to discern traditional models that might speak the rhetoric of social inclusion from models that have features such as offering individualised and enabling paths to participation through such things as supporting people into valued roles and relationships. The challenge for leaders then is to deepen their understanding of and vision for social inclusion, and to be

astute in recognising rhetoric and the limits of traditional models.

2. Confront the values questions

Gallagher (2001) identifies that social inclusion is seen to be either a moral issue or an issue to be decided based on empirical evidence. She argues that empirical arguments against inclusion are not values-neutral, and in fact are based on (inaccurate and unhelpful) ideologies. These ideologies include an acceptance of the accuracy of labelling and categorising and their potential to determine the capacities of people with disabilities; acceptance of the sorting functions of schools; acceptance of the assumption that segregated classrooms are protective; and the denial that decisions about the shape, size and operations of regular classrooms were themselves based on assumptions that could be false. She concludes that it is not possible to only consider empirical arguments; that actions towards (or away from) social inclusion must start with 'a struggle of conscience' about what type of world we are creating (Gallagher, 2001: 651).

Arguments that purport to *only* have an economic base (eg. social inclusion is more expensive or too expensive), a human resource base (staff are untrained), or a human capacity base (eg. the community will never accept people, and that the community is dangerous) also have a values base.

It is essential for leaders to be engaged in questions about values. Duggan (2005: 36) issued an invitation to 'contemplate our shared humanity', and gave encouragement, 'Please try to do your very best to see past and through my disability. For it is when this moment arrives – and not before! – that we can encounter one another as truly human beings' (Duggan, 1999: 38).

Thus, questions arise such as to what extent are people with disabilities fellow human beings who also crave purpose, meaning, participation, relationships and belonging? To what extent can we imagine ordinary citizens wanting to engage with someone who embodies characteristics that our society does not value? Exploration of these and other values questions are fundamental to any action for social inclusion.

Cautions regarding a superficial adoption of a values base have been issued. Kendrick and Sullivan (2009) caution against 'a convenient and fuzzy political slogan' (p67). Armstrong

(2007) cautions against an ideological embrace of the notion of an inclusive society that is expressed in mantras such as '*acceptance of diversity*' and '*our society should be inclusive*'. He based this caution on the contemporary dominance of modernism, which elevates self-interest above the interest of others or the collective. This is so strong in Western society that it is highly unlikely to facilitate easy or automatic social inclusion of people with negatively valued characteristics. Further, it is ineffective to simply claim the 'rights' of people to be included, as without the helpful underpinning values, either rights will not be accorded or they will be accorded in a mean-spirited way.

The challenge is for leaders to explore their own values and assist those around them to do the same, so that these conscious values can both inspire and lead them to action, and so that the action is coherent with their values.

3. Be conscious of what the community is taught through the actions of services

Kitchin (1998) asserts that people with disabilities are not only '*kept in their place*' by power differentials, unconcern and ignorance, but also by the physical environments that communicate to onlookers that they need to be with each other and do not belong to ordinary life. This is so strong that when people with disabilities are seen in everyday physical environments, they are frequently deemed to be 'out of place'. Further, people with a valued status accept this as natural and commonsense and typically do not question it. Armstrong (2007) named this as the low consciousness that human beings have for their own capacity to devalue others.

Lee (2007) points out that the community is witness to what services and service workers do. So therefore citizens with preconceived notions about people with disabilities will have them confirmed through witnessing the ways that people are spoken and written about and to, the size of the groups that people are taken out and about in, that groups are made up of people with disabilities only, that the physical environments where people spend their time and the activities that are done there may not be age appropriate or conducive to the development of capacities.

Lee further articulates that services teach the community about the place and worth of people with disabilities through the actions of services, such as that services mediate any involvement between a person with a disability and an ordinary citizen and utilise processes such as approval processes, training and registration and therefore give the impression that only a professional service can meet the needs of someone with a disability. Compounding this emphasis on 'professional care only', services act as if the community is fearful of people with disabilities, which turns staff into guards.

The challenge is for leaders to create opportunities and support arrangements that do not reinforce the preconceived low expectations about people with disabilities, and that extend the minds of citizens to see the possibility of the gifts, strengths and contributions of people with disabilities to community life. Thus it is when individuals with disabilities are supported to be in valued roles, in ordinary places, doing ordinary things with ordinary citizens that citizens are likely to have their preconceived ideas confronted. This is attitude change at a grassroots level.

4. Transform the role of services and workers

This challenge refers to the need for leaders to lead change and innovation in human services and systems, and requires leaders to come from a solid theoretical and practice base that is very different from the basis of traditional services.

For decades and longer, the service system is such that the dominant paradigm is one where people with disabilities are in community but not of community. Lemay (2006) points out that while there are many people with disabilities now living and moving about in ordinary communities, they do not have the levels of participation and social networks that would be expected. This raises the question about what is happening here. If services are not enabling people to participate in community life and facilitate the development of relationships, what are they doing?

O'Brien (1999) observes how different group homes are from real homes; how unlike sheltered workshops are to places of business and how disparate special schools are from regular schools. Jackson (2008) and Lee (2008)

identify some of the ways that group homes are not typical homes: the physical features such as the size of the home, the presence of a staff room, the grouping of individuals who share little other than having a disability serve to reinforce pre-existing ideas about the 'otherness' of people with disabilities and lead to rejecting behaviours by local neighbourhoods.

Traditionally people with disabilities have been 'placed in' services (O'Brien *et al*, 2001). Services become receptacles for people with disabilities: if people have needs, there is an expectation from communities, families, people with disabilities and services themselves that the service (and only a service) will meet those needs. Staff who are 'velcroed' to the people they are supporting inevitably create dependencies and emit messages to citizens about the inabilities of the people they support and the inabilities of community members to be involved.

Lemay (2006) notes that social isolation is related to the paucity of valued social roles in people's life that would otherwise be natural pathways to relationships. It could be deduced that this situation is likely to arise if support workers mainly confine themselves to personal care and housework and thus have largely become minders.

Evolution of services, systems and the role of service workers must be toward a paradigm whereby services facilitate needs being met, where the role of the service is to provide the supports to enable people to be actively participating in home and its associated neighbourhood life, work, leisure passions and interests, spirituality and the associated social lives in all of those domains. This signals a shift from the role of worker as carer, minder, protector and mediator to one of a facilitator of opportunities, guide to ordinary lifestyles and relationships, mentor and encourager for learning new things, and interpreter of the ways of the community. This indicates that one of the very helpful things that services could be doing to support people in social inclusion is to support them to have valued roles such as homemaker, neighbour, employee, club member, hobby enthusiast and family member.

Thus, this challenge is about change, transformation, evolution and innovation.

Kendrick and Sullivan (2009: 71) point out that '*a more common pattern in change is the evolution of positive examples of what is being sought, arising from very small instances of social pioneering and experimentation*'. They are describing one potent way that change can happen: to try new things and build upon the positive examples.

5. Use theory-based knowledge

The leadership challenge is also to find those theories and approaches that will assist the work for social inclusion. Theories explaining social devaluation, the experiences of social exclusion and paths to valued roles such as social role valorization (Wolfensberger, 1998; Race, 1999) are highly relevant and helpful. The power in supporting people into valued roles is that this dynamic not only enables people to be in roles of participation and contribution, with increased opportunities for relationships, but also influences how a person with a disability is perceived.

Leaders should also look to frameworks and approaches regarding how to work in and with community. Work with ordinary citizens that assist them to resist the impulse to reject could be derived from community development approaches. What is not meant here is community development that leads to the development of services and the use of paid workers. The more relevant branch of community development is exemplified in Westoby and Owen (2009) who present a helpful practice framework involving '*particular kinds of communication and action that build community*' (p1). This results in a web of relationships, where the paid worker is not the central pivot of these relationships.

The work around bridging and bonding social capital is also highly relevant. Knudsen and colleagues (2007) cite Putnam in describing social capital as '*the social ties, connections, networks, and norms from which individuals and collectivities benefit*'. Bonding happens between 'like' people, such as through bringing socially isolated people together. The benefit is that people are brought together through a shared plight or interest, and so people can feel less alone. The risk, however, is that this serves to isolate groups on the basis of the homogeneity, and they can become stuck in

a cycle of shared plight. This is what happens in congregated services for people with disabilities. Bridging social capital exists when there are connections developed between a range of marginalised and non-marginalised people so that people have access to a range of information and resources. It is this form of social capital that will be helpful to the social inclusion of people with disabilities.

What the leadership attributes might be

Thorough and thoughtful work for social inclusion is more likely when leaders show a coherence between values, thinking and action. Authentic leadership is more likely when five conditions are present.

1. Leaders have a moral and ethical base

The values and beliefs that the leader holds at a deeply personal level reflect such beliefs that humanity is shared between all humans. Heart qualities include compassion and a deep feeling for the plight of people with disabilities who are excluded on the basis of negatively valued difference. Qualities such as hope, optimism and courage are present.

These are necessary because in working for social inclusion, the leader is first working against the natural inclination of humans to reject and exclude and thus is working contrarily to the dominant groups in our society. Second, the leader is working against the forces in our society that keep people as 'other'. The moral and ethical base is a foundation for what happens at a knowledge level.

2. There is a combination of conceptual clarity, insight, knowledge and wisdom

Utilising a sound theoretical and practice base, such as that recommended previously, builds on sound values and ethics. One without the other will be insufficient.

Turnbull and colleagues (2009) suggest the importance of wisdom-based action in facilitating social inclusion, through being attuned to values, vision and context; utilising and evaluating knowledge, using discernment to plan next steps and take action that includes action learning, and connections to allies.

3. There is authentic relationships with people with disabilities and family members

This provides an anchor to the reality of rejection and exclusion in people's lives and provides a spur to action. Without this anchor it is difficult for a leader to be mindful about what is at stake for people with disabilities. With this anchor, even though it may be difficult to bear witness to social exclusion and its impacts, the leader is more likely to want to make a potent difference and inspire others to do so also.

4. There is an appreciation of history

Service systems across time are riddled with 'new ideas' and 'new services' that are in actuality a re-creation of responses from times past. Respect for history leads a leader to realise that not everything purported as 'new' is in fact new, and is certainly not necessarily good or helpful. For example, residential buildings continue to be built and might be called 'villages' but are actually repeats of the group home context that has been in evidence for decades.

5. Leaders put their faith and efforts in things that are likely to bring dividends

It is highly unlikely that better assessment processes, better planning processes, more money, better training etc will make the real and lasting differences in the lives of people with disabilities. Nor will an over-reliance on standards and compliance-based audits as measures for quality. The key measures for quality need to be what people with disabilities experience on a day-to-day basis and, in terms of social inclusion, the extent to which they participate in community life in a range of roles and with a range of relationships. The solutions are more likely to lie with values-based qualities in the leadership and the staff, the theoretical underpinnings to the work and real work in and with community.

Conclusion

Even though societal and personal human habits that lead to social exclusion are deeply ingrained, there is the possibility for the transformation of our services and communities. With regard to the social inclusion of people with disabilities and responses by those in

leadership roles, five leadership challenges have been explored, and five helpful attributes of leaders have been identified. It is up to us.

Implications for leadership in practice

Leadership for social inclusion aims to:

- deepen the conceptual understanding and thinking of leaders
- create an ethical base that fosters and rewards efforts towards authentic social inclusion
- recruit ethical leaders with the capacity to imagine better lifestyles for people with disabilities
- commit to quality responses that are measured by the extent to which each person has valued roles and freely given relationships
- transform group-based and building-based responses to responses that are individualised and that enable valued roles for participation in community life
- transform the role of staff from carers and minders to developmental roles such as enabler, guide and bridge builder.

Address for correspondence

Jane Sherwin
Consultant, New Zealand
36 Annie Street
Paddington
Brisbane
Queensland 4064
Australia
Email: sherwinconsulting@gmail.com

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Endnote

¹ In New Zealand, and throughout this article, the term 'disability' encompasses intellectual/ learning disability, physical and sensory disabilities.



Jane Sherwin is an Australian-based consultant who has been involved in the lives of people with disabilities since the late 1970s. She is a scholar-practitioner and is committed to working at a grassroots level towards a system of responsive services and supports, and towards arrangements whereby vulnerable people experience meaningful lives and greater levels of control over their own support arrangements. Jane works with groups and organisations on matters to do with values based quality, person-centred approaches, social inclusion and leadership development. She has been involved in social change efforts since the early 1990s, using organisational change, training, mentoring and writing as key strategies. Jane is a Senior Trainer in the theory of Social Role Valorisation.