SUBMISSION TO PRODUCTIVITY COMMISSION

MELINDA JONES

About The Author:

I am the mother of 5 adult children, two of whom are people with disabilities. I am also a retired academic on a disablement pension and a human rights lawyer. Some of my expertise is in the area of the rights of people with disabilities. My most recent publication are chapters on "Inclusion, Social Inclusion and Social Exclusion" and "Valuing All Lives – Even 'Wrongful' Ones" in *Critical Perspectives on Human Rights & Disablity* (ed Rioux, Basser & Jones, Brill due for release May 2011), a final draft of the former I have attached to this submission.

Although I am an educated professional and a person with a disability myself, I am a full time carer. I am unable to be absent from the home for 24 hours – let alone have a serious break. My husband (their father) is away from home, working both interstate and overseas, and I am therefore effectively a single parent. I have been unable to access appropriate respite, even at times of crisis. Fortunately my other children provide me with significant support.

The Principles Involved:

Any new scheme to facilitate the inclusion of people with disabilities in Australian society should be based on principles of fairness, equality and justice. Any scheme to be adopted must ensure that the fundamental rights of people with disabilities, as contained in the Disability Convention, are respected. The objective should be to improve the position of people with disabilities by ensuring that needs arising from the individual experience of disability are taken into account. In particular, treating people with disability with respect requires a recognition that many people are multiply disabled and that the whole person must be taken into account. Further, where the experience of disadvantage arising from disability is compounded by an intersection with race, gender, NESB or membership of another category of disempowerment, the interventions proposed must be to overcome the whole experience of the person.

From an economic perspective, it is essential to recognize the considerable financial burdens occasioned by disability, and that poverty and financial hardship go hand-in-hand with disability in Australia as the situation currently stands. The potential of an NDIS to improve the position of people with disabilities is great. Distributive justice requires that, at a minimum, people with disabilities receive a greater share of social resources, as without significant support, people with disabilities face a crippling with debt and risk sinking into poverty. However, will very much depend on the terms of the particular scheme adopted.

Fundamentally, economic justice requires that people with disabilities are able to spend their income, whether from employment or from disability support pensions, on the same goods and services and in the same manner as all other Australians. That is, the income of people with disabilities should be available to:

- Pay for housing: either in the form of rent or mortgage repayments
- Purchase food
- Purchase clothing
- Pay the cost of utilities
- Pay for leisure and social activity

The only possibility that people with disabilities will be able to spend their incomes in this basic way, equally with other Australians, is to ensure that the extraordinary costs of disability are met independently of personal income. Further, the meeting of the financial burden arising from disability will facilitate independence and the potential of people with disabilities to participate in society. This, in turn, may lead to the capacity of some people with disabilities to participate in the workforce, thereby defraying some of the cost of disability to be borne by families and the state.

Executive Summary

I support the NDIS and the advent of a NDI Authority. This will improve the quality of life of all Australians with disabilities and facilitate inclusion and social participation.

My recommendations are:

Recommendation 1: That the NDIS covers the full cost of medical and paramedical needs of people with disabilities independent of income. This must include mental illness support and funding for the cost of health professionals. The Health Care Card, for eligible people with disabilities only, should be replaced by the NDIS.

Recommendation 2: All funding for the support of people with disabilities to ensure inclusion in mainstream education should be administered by the NDIS and tied to the individual student. This includes personal assistance in educational settings and other material support to facilitate inclusion. The funding must be flexibly tied to the individual to take into account changed circumstances, including relocation. (While the organisation and administration of funding for education-specific supports would appear better handled by schools or school systems, it is impossible to demarcate which supports are and are not 'education- specific')

Recommendation 3: While it would be inappropriate for NDIS to become a provider of all services or to attempt to cover the field, the NDIS should be able to engage with all the extraordinary costs associated with disability in every area of life and with respect to all services when required for a particular individual – whether it be a matter of health, housing, transport or mainstream education.

Recommendation 4: Any person on a disability support pension should be eligible for support under NDIS.

Recommendation 5: Any person on government benefits and/or a low income, or holding a health care card, who also has a disability, should be eligible for support under NDIS.

Recommendation 6: Unless there is an administrative reason (or other good reason) to list intellectual disability separately, and beyond 'core activity limitation', it ought not be specified.

Recommendation 7: That the government fund educational providers to train disability workers.

Recommendation 8: When support services are required, in any settings, the qualification of parents and carers should be recognized (as prior learning) such that carers and parents receive payment for their support role. Accountability on par to that of other workers should be implemented.

Recommendation 9: The NDI Authority work with disability service providers, particularly those running 'day programmes', and local councils to provide accessible community centres which provide a full range of educational, social & leisure activities available for use by all members of their community, including those with disabilities. To meet the needs of people with disabilities, and to offer choice, a range of concurrent activities must be available.

Recommendation 10: In the funding or establishment of programmes, attention should be paid to the safety of young women and members of other vulnerable groups (such as gay & homosexual men & women).

Recommendation 11: The NDI Authority work with disability service providers to ensure that services are not 'one size fits all'. The provision of single sex activities as well as those targeted loosely to specific age-groups should be taken into consideration.

Recommendation 12: The NDI Authority should seek to establish more out of home respite and holiday opportunities. It should be a matter of policy that all people with disabilities have the opportunity to have 2-4 weeks of holiday throughout the year and that there is funding and accessible holiday options available.

Recommendation 13: That the NDI Authority establishes the housing needs of all those who are supported through the NDIS, and works with governments to ensure adequate & suitable housing is available within a reasonable time of the need arising.

Recommendation 14: That the NDI Authority ensures that there is supported accommodation available to meet the religious & cultural needs of individuals (including the availability of single sex housing and housing where religious rules and rituals are respected) and which allows the person with a disability reasonable access to the community into which they have been included.

Recommendation 15: The NDI Authority should ensure that all supports for people with disabilities should be available according to principles of distributive justice and on an equal basis.

Recommendation 16: That all operational rules governing the NDIA are transparent and that clear criteria for eligibility are provided.

Recommendation 17: That the NDIA should operate as an information hub and have staff to help people with disabilities navigate the system'

Recommendation 18: With respect to decisions of the NDIA, a review process including internal review & judicial review be put into place. All people with disabilities should be made aware of review rights

Issues Arising from the Proposed NDIS

A. *The exclusion of services such as health, public housing, public transport and mainstream education and employment services.*

The continued separation of services will impact negatively on people with disabilities. To the extent to which people with disabilities are satisfactorily accommodated by the existing system, and to the extent to which there is sufficient access to these services, it is not essential to make changes to existing arrangements. It is essential, however, that the new agency is able to be proactive with respect to all areas of need of people with disabilities, and there should not be artificial boundaries drawn. It would be preferable for the NDIS to have powers with regard to these areas but only for people with disabilities.

Problem arising from division into the specific areas of life are responded to below:

1. Health services

While Medicare may cover a high percentage of the costs of public health for some people, for many people with disabilities who have chronic illness or medical problems accessing health services are financially crippling as well as further disabling. Medicare does not, for example, cover the cost of physiotherapy, occupational therapy, dental issues, pilates, audiology or psychology. There are not sufficient services provided by the public system to meet the needs of existing users. There is no way that currently unmet needs can be accommodated.

My experience: *My daughter D has a chronic illness, which has proved significantly more disabling than imaginable. She had 56 hospital admissions by the time she reached 18.* ***Every cent of her disability support pension*** *is spent on: medication; payment to health professionals; payment for medical services; and purchase of equipment. As such, it is left to the family to bears the cost of living - rent; food; clothing; utilities; medical insurance; other costs associated with health care not covered by the disability support pension; and leisure and social activity. My family simply falls further and further into debt.*

Proposal:

It is essential for people with chronic illness, in particular, to have the equivalent to top cover private health insurance, plus access to funding of gap payments, at the very least. The current cost of medical insurance is prohibitive and eats up a high percentage of the Disability Support Pension. The linkage of the Health Care Card to the Pension provides an incentive to remain outside the workforce; while lack of occupation is a clear indication of mental illness. A means must be found to ensure that the right to health is meaningful for all Australians with disabilities.

It is not clear from the Report that medical costs – in particular, the cost of medical professionals – are included in the NDIS proposal. Yet medical intervention – from surgery to consultation – is extremely costly. Most often, a person with a disability will be unable to access even urgent medical support for lack of money. In particular mental health support of both people with disabilities and carers is essential.

Recommendation 1: *That the NDIS covers the full cost of medical and paramedical needs of people with disabilities independent of income. This must include mental illness support and* *funding for the cost of health professionals. The Health Care Card, for eligible people with disabilities only, should be replaced by the NDIS.*

2. Education

While there is no reason for an insurance scheme to replace the obligation of schools to act in a non-discriminatory manner and to include people with disabilities, the availability of funding for support staff, aides and equipment should not be determined by postcard. Funding should be sufficient to ensure that people with disabilities have access to education on equal grounds to all other Australians. Further, it is absurd to have to 'prove your disability' to a body which may use different criteria for establishing disability and need. There is often duplication of services when these are provided though a range of schemes.

It is also the case that much of the funding for inclusion of children with disabilities takes the form of personal care supports identical to those needed for an individual to participate in the community. It seems absurd that this funding should be context specific. Education is a most basic form of inclusion and social participation.

The implication of the inclusion of 'mainstream schools' in the NDIS list of exclusions suggests that there will be support for special schools. As the latter are inconsistent with the International Disability Convention, and are sites of exclusion, it is inappropriate attendance at special schools to be the only way of receiving appropriate support.

My experience*: When my daughter was effectively (and probably unlawfully) excluded from an independent school at the end of 1st term of Year Ten. We could not find any school that was prepared to accept her at that time. Other independent schools argued that at that point of the school year they were unable to provide her with the support she needed; state schools suggested that she come back the following year after applying for funding at the end of the current year. Such situations only arise because educational support funding is not personalized and not national.*

One consequence of leaving school was the loss of services she had been funded for by the school. In particular, she went from having weekly OT, which had been funded for the whole school year. Her last session was in April that year and the rest of the funding simply disappeared – never to be applied to my daughter again.

Proposal: The NDIS provides for the portability of individualized packages, to allow individuals autonomy in their lives, including the ability to move between service providers. With respect to education, there is portability within the various systems, but not between systems. For example, funding for a student attending an independent school is, at least in Victoria, only transferable to another independent school. Should the student wish to move to the public sector, they will lose finding. While this can be reapplied for, students may have long periods with no supports as these will not be available until money is concerned.

Recommendation 2: *All funding for the support of people with disabilities to ensure inclusion in mainstream education should be administered by the NDIS and tied to the individual student. This includes personal assistance in educational settings and other material support to facilitate inclusion. The funding must be flexibly tied to the individual to take into account changed circumstances, including relocation. (While the organisation and administration of funding for education-specific supports would appear better handled by schools or school systems, it is impossible to demarcate which supports are and are not 'education- specific')*

3. Public Housing

Adapting public housing to meet the unmet needs of people with disabilities to housing should be covered by NDIS. There is insufficient supported accommodation, and it makes no sense to ignore alternative housing potential. Further comments about housing are noted below.

4. Public Transport

While it is not the task of NDIS to address the problems of the various public transport systems, the intersection between disability and mobility is certainly an agenda item. Some people with disabilities will be able to use public transport, others will only be able to do so with support. Funding for extraordinary public transport costs should be covered by the NDIS. Taxi vouchers are available to some people with disabilities. In Victoria this is a half price taxi scheme. As a result, some Victorians with disabilities will be limited in the social action by the prohibiting cost of the half-price.

Recommendation 3: *While it would be inappropriate for NDIS to become a provider of all services or to attempt to cover the field, the NDIS should be able to engage with all the extraordinary costs associated with disability in every area of life and with respect to all services when required for a particular individual – whether it be a matter of health, housing, transport or mainstream education.*

B. Eligibility Criteria: "The Three Tiers"

1. People limited in core life activity

It is important that all people whose ability to participate in core functions & activities are covered by the NDIS independent of any classification of disability type. Equally, we do not, in Australia, embrace a notion of the "worthy disabled", and must not disadvantage people with disabilities due to the source or background to their disability. Equally, we do not generally consider that only some people are "qualified" people with disabilities. As such, eligibility should be exclusively dependent on the existence of limitations to the ability to function and participate in society on equal terms as a result of disability.

One easy class of people to be included is 'anyone receiving a disability support pension'. Those receiving disability support pensions have already established their inability to participate in the workforce. As one criterion for receiving the disability support pension is the existence of a disability, pension holders should not be required to 'prove' their disability a second time. This is one way of ensuring people with non-mainstream disabilities are not left having to prove entitlement. Instead, the focus can be on the support required – whether this be a nebulizer or respite. For example, a person with a chronic illness may be severely limited in core activities but is not always considered to be a person with a disability. It would be unjust to reject such an applicant for NDIS support if Centrelink accepted the disability and granted a disability support pension.

My experience: *Of my 2 daughters who have disabilities, the one with a chronic illness is far more disabled by her condition than the one with a genetic disorder, an intellectual disability & a host of other physical & psychiatric conditions. It is impossible for my daughter with a Chronic Illness to do anything full-time. She was unable to attend school regularly – of the times she was enrolled she attended no more than 2 days a week on average. When she was at home (officially doing distant ed or OTEN) I could get no support of any type. The one time I was granted 6 hours a week support, the organization could not find anyone to fill the role. It took many years before I realised that she had a disability – so throughout her childhood I did not receive a child disability allowance for her. This meant that she had to be home on her own for hours and days at a time. Once we thought of the problem as disability, it became possible to imagine support – even if none were available.*

Recommendation 4: *Any person on a disability support pension should be eligible for support under NDIS.*

Another group who should be eligible to apply to the NDIS are those with health care cards and/or other government support. Clearly, not all such people have disabilities, but for those who can provide evidence of even relatively minor disabilities should be eligible to apply for support from the NDIS. Such support might dramatically alter the life of a recipient, as it is most likely that the cost of rectifying minor disabilities is prohibitive for those with low incomes. The level of support required may be very low – for example hearing aids or technological devices such as IPads or IPhones may be a few hundred dollars every 3 years – but the overall benefit not just to the individual but to society as a whole is high.

My experience: *I have an acquaintance who has a significant hearing loss and is on a low income. Although not bad enough to be a "disability", her ability to gain and keep employment is dramatically affected by her hearing. She is unable to afford hearing aids while unemployed or even in the operation of her own business. She was almost granted funding for hearing aids during a period of employment, but lost the job before the application was processed. She therefore lost eligibility and has been unable to find other employment. The simple expedient of hearing aids would have a profound impact on her social abilities and her social and economic contributions to the society at large.*

Some people with disabilities are dependent more on the health care benefits than on the disability pension. As such, many people with disabilities who are able, for example, to manage part-time work and could afford (and would be willing) to replace the pension with earned income, are careful not to put the health care card at risk. Should the NDIS provide support to replace reliance on the healthcare card, this would potentially bring a net saving to the government. It would also improve the self-esteem of the individual and allow for greater dignity.

Recommendation 5: *Any person on government benefits and/or a low income, or holding a health care card, who also has a disability, should be eligible for support under NDIS.*

2. The specification of intellectual disability.

The list of those covered by the 3rd Tier includes "intellectual disability not already included". The reason for this is unclear. Why should a person with an intellectual disability be eligible for NDIS support unless the impact of his or her disability was to limit core activity? Surely those with readily correctable vision loss or those with correctable impaired hearing are not included unless they are limited by their vision or by their hearing.

Recommendation 6: *Unless there is an administrative reason (or other good reason) to list intellectual disability separately, and beyond 'core activity limitation', it ought not be specified.*

3. Early intervention

It is important that early intervention is seen as a means of preventing or limiting the impact of disability. There are many people who do not consider themselves to be people with disabilities, but who are only able to remain outside the classification by access to aids. These people need support but seem to fall through the gap. Early intervention would increase the quality of their lives and their contribution to the economy.

C. Choice of Support

There is a significant shortage of service providers and qualified support workers. Educational infrastructure will need to be established to create a field of Disability Care Workers who are paid appropriately. In the interim, support could continue to be provided by parents and carers, but in a paid rather than voluntary capacity. This would help the chances of families breaking out of the poverty cycles.

Recommendation 7: *That the government fund educational providers to train disability workers.*

Recommendation 8: *When support services are required, in any settings, the qualification of parents and carers should be recognized (as prior learning) such that carers and parents receive payment for their support role. Accountability on par to that of other workers should be implemented.*

D. Supports provided by NDIS

While the list of supports to be provided by NDIS is comprehensive, there are some specific comments I would like to make.

1. Personal Care:

A significant improvement of the lives of many people with disabilities – particularly those with chronic illness – will be greatly enhanced by support in the area of health maintenance, nursing care, medication use and regular exercises.

As per recommendations 8, existing care givers should be able to be paid for performing a service, particularly if there is no suitable alternative available.

2. Community access supports:

Most communities have inadequate social structures in which to include people with disabilities. One solution is to restructure existing day programmes and create community centres in which the types of activities currently available to a limited number of people (those using the day programme) would be run and available to the whole community. Where this has been done, there has been significant improvement in the quality of lives of members of the community, and people with disabilities have been accepted as members of the community.

Recommendation 9: *The NDI Authority work with disability service providers, particularly those running 'day programmes', and local councils to provide accessible community centres which provide a full range of educational, social & leisure activities available for use by all members of their community, including those with disabilities. To meet the needs of people with disabilities, and to offer choice, a range of concurrent activities must be available.*

One issue of concern to me is that once a person leaves formal education, there is an assumption that activities for "anyone from 18 – 65 years old" are appropriate for all adult people with disabilities. This is particularly difficult for young women with intellectual disabilities. Not only are these women often much younger than their chronological age, young women with intellectual disabilities are particularly vulnerable to sexual abuse (the literature suggests that somewhere between 70% - 98% of all young women with intellectual disabilities have been sexually assaulted by the age of 18).

Recommendation 10: *In the funding or establishment of programmes, attention should be paid to the safety of young women and members of other vulnerable groups (such as gay & homosexual men & women).*

It is also important that there be some single sex activities available, for otherwise the services will discriminate against women from religious Muslim or Jewish backgrounds, who will not be able to participate in mixed social activity.

Recommendation 11: *The NDI Authority work with disability service providers to ensure that services are not 'one size fits all'. The provision of single sex activities as well as those targeted loosely to specific age-groups should be taken into consideration.*

3. Respite

There is a significant shortage of respite options, especially where complex multi-natured disability is concerned.

***My experience*:** *My daughter is one of many people with intellectual disabilities who also has a mental illness. During my last crisis, I approached every respite service I could find. Those services which were happy to look after a person with an intellectual disability were unwilling to take on a* *person with active mental health issues; those services which were happy to look after a person with active mental health issues were unwilling to take on a person with an intellectual disability (specially where there are personal support needs).*

Holidays (away from normal residence) should be available to all people with disabilities, but this will only be possible if holiday activities are available and appropriately funded. This would provide respite for carers as well as a positive social experience for people with disabilities. A holiday must not be a period of time where the person with a disability is left at home with no social outlets. Perhaps grants should be available to all people with disabilities to facilitate activity during periods of time when regular activities are unavailable (term or Xmas breaks for example).

Recommendation 12: *The NDI Authority should seek to establish more out of home respite and holiday opportunities. It should be a matter of policy that all people with disabilities have the opportunity to have 2-4 weeks of holiday throughout the year and that there is funding and accessible holiday options available.*

4. Specialist accommodation support, such as group homes and alternative family placement

Housing for people with disabilities is, perhaps, the most urgent problem to be addressed. Not only are there insufficient places, but where it is simply not viable for a person to be supported at home, people with disabilities and carers and are forced to compromise in a manner that would not be vaguely acceptable for any other people. Accommodation must be available within the community within which the person with a disability has been included. Accommodation must be available to meet the religious and cultural needs of the individuals to be housed & supported. This must include:

- Single sex housing;
- Housing where religious rules are respected (including holiday observance and dietary requirements); and
- Housing that allows reasonable access to the community in which the person has been included.

Recommendation 13: *That the NDI Authority establishes the housing needs of all those who are supported through the NDIS, and works with governments to ensure adequate & suitable housing is available within a reasonable time of the need arising.*

My experience**:** *In late 2010 the many doctors and therapists in my daughter's care team were all very much of the opinion that Elisheva should move out of the family home into supported accommodation. This arose as a result of my daughter discovering that there was a vacancy in a friend's house, which was operated by Jewish Care. As Orthodox Jews, supported accommodation would only be suitable if it met some specific criteria. These include: observance of Jewish dietary laws and walking distance to the family and Synagogue we attend. The latter is essential as no form of transport is allowed on Friday night, Saturday or on any major Jewish festival. These are also the time of all family social activities (we have family gatherings every Friday night, every Saturday and every Jewish festival). Ideally, it would be more appropriate for my daughter to live in a single sex house, but I have been "assured" by Jewish Care that this would contravene DHS rules. (Although we would contemplate mixed housing, many other Orthodox Jews & Muslims would not. If Jewish Care are correct, a significant number of people are been discriminated against in the provision of supported accommodation.) The house in question met our criteria, and I have since established that there is no other house that could meet Elisheva's needs. This was not, however, the criteria used to allocate the place. As a result, Elisheva will have to wait until there is another vacancy in that house and hope that she will be able to have the greatest need at that particular time.*

One problem with the current process, which must be addressed by the NDI Authority, is the lack transparency of the housing process. This is no doubt true of other aspects of the allocation of resources. It is wrong that I was advised to "play the system" – to ring DHS every day in tears to say how urgent is the need for Elisheva to move out. I was also advised that I would get housing if I abandoned my daughter by refusing to bring her home from hospital. This is totally unacceptable. An objective, transparent process and an appeal system should both be put into place.

Recommendation 14: *That the NDI Authority ensures that there is supported accommodation available to meet the religious & cultural needs of individuals (including the availability of single sex housing and housing where religious rules and rituals are respected) and which allows the person with a disability reasonable access to the community into which they have been included.*

5. Therapies such as occupational, physiotherapy and counseling

Support for this is essential, especially given the degree of disability experienced by those with chronic illnesses. The cost of para-medical support is prohibitive and, as a result, many people with disabilities simply do not receive the help they urgently need.

E. The National Disability Insurance Authority

One problem with navigating the existing rules pertaining to disability services is that there are multiple overlapping services all of which have limited application. What services are available to any person with a disability vary dramatically depending upon where one lives and classifications of disability. Many people with disabilities receive no services, often because the task of dealing with the bureaucracy is far too complex for a frazzled carer or an overwhelmed person with a disability. It is crucial that the system become equitable and that principles of distributive justice are applied. A major benefit of a national scheme is that all people should have equal entitlements and the ability to gain access to services should no longer be a mattrert of luck. Further, with a national system, pathways to eligibility should be made clear and the process simplified.

Recommendation 15: *The NDI Authority should ensure that all supports for people with disabilities should be available according to principles of distributive justice and on an equal basis.*

The NDI Authority should ensure that the processes of eligibility and the availability of services are clearly laid out. The NDI Authority should operate as an information hub, and should have staff available to help people with disabilities and carers to understand all aspects of disability law and policy, as well as information about available resources and supports. The application process should be simple, and rights of people with disabilities should be clearly specified. Rules relating to the administration of the NDIS should be made by 'the Minister' and should take the form of Regulations. This would allow transparency and scrutiny to ensure that the subordinate legislation is consistent with, inter alia, human rights principles.

A significant aspect of the difficulties facing people with disabilities and carers, beyond the 'confusopoly', is the lack of clarity regarding administrative processes and accountability. It is therefore important that the NDIA be structured in such a way that decision-making processes are clear, the chain of authority transparent and that a review process is available both within the NDIA and through the courts. My preferred model is:

- Original decision-maker
- Designated Internal Reviewer
- An administrative tribunal (either *sui generis* of the AAT)
- Judicial review under the ADJR

Recommendation 16: *That all operational rules governing the NDIA are transparent and that clear criteria for eligibility are provided.*

Recommendation 17: *That the NDIA should operate as an information hub and have staff to help people with disabilities navigate the system'*

Recommendation 18: *With respect to decisions of the NDIA, a review process including internal review & judicial review be put into place. All people with disabilities should be made aware of review rights.*

INCLUSION, SOCIAL INCLUSION & PARTICIPATION

Melinda Jones

The principle of inclusion is simple. It is the opposite of exclusion and also of alienation. It is the principle that says that whatever benefits accrue to members of a society are the heritage of all people, not just those who are able-bodied. Inclusion means that all people are entitled to full membership of the human family. Within the large group of humanity, just as in any family, people play a number of different roles and bring to the community a variety of needs, vulnerabilities, skills and experiences. Each individual operates in relation with others and each of us is inter-dependent. Inclusion requires the recognition of self in other, and other in self.[1]

Fundamentally, inclusion is the principle that we are all entitled to participate fully in all aspects of society; that we all have the same rights and responsibilities; that we all have something to contribute. It is the principle which demands valued recognition of all people and the entitlement of all to meaningful interaction, involvement and engagement in every part of the complex, multifaceted societies in which we live. Whether at school or work, in clubs or cinemas, in playgrounds or at beaches, at the health centre or the supermarket, the right to inclusion requires that people with disabilities are not merely seen, but are heard and acknowledged.

Inclusion is the right of the individual and the responsibility of society as a whole. Inclusion requires the removal of barriers and social structures which impede participation. It requires proactive policy making, lateral thinking and on-going commitment. Inclusion is a realistic and pragmatic principle. It accepts the reality of disability and difference, and acknowledges that while medical treatment and rehabilitation have a role to play in improving the physical position of people with disabilities, these can never, on their own, provide for the rights of equal citizenship and of social solidarity. Inclusion is about valued recognition, meaningful engagement and enabling social policy.

Three Dimensions of Inclusion

In order for people with disabilities to be included in society, each of the three dimensions of inclusion must be operational. These are: a non-discriminatory attitude towards people with disabilities; the guarantee of access to participation in every area of life; and the facilitation of people with disabilities to limit the impact of disability.

Because inclusion ultimately depends on the acceptance of difference and the willingness to celebrate diversity, there must be an environment and political will to combat discrimination and to promote equality. While people with disabilities are shunned or locked away, stereotyped or viewed as outsiders, it is unrealistic to expect inclusion. Negative perception and treatment will not necessarily occur across all aspects of society or with respect to all types of disability. The inclusion of some people with disabilities may pave the way for a change of attitude with respect to other people with disabilities. An appropriate attitude to people with disabilities should not be taken for granted. Inclusion is predicated upon good interaction between people with and without disabilities. It is the attitude adopted by society which determines the extent to which inclusion will be achieved.[2]

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[1] Habermas, J (1987) *The Philosophical Discourse of Modernity* Polity Press, at 310

[2] See Morris J (1991) *Pride Against Prejudice: Transforming Attituudes to Disability* Women's Press; and C Goggin & C Newell (2005) *Disability in Australia: Exposing a Social Apartheid*UNSW Press

One of the greatest hurdles confronting people with disabilities is the understanding of disability in terms of individual pathology. Described as the medical model of disability, this perspective considers disability to be a deficit in the individual which prevents the person from reaching the benchmark of ‘normal’.[3] Disability is seen as a personal tragedy, presenting hurdles which only the individual can confront. Often the person is reduced to a condition or impairment, and the only assumed need is for medicine and rehabilitation. While not underestimating the importance of these, where appropriate, or discounting the reality that people with disabilities are disadvantaged by their bodies or minds, the focus on individual pathology has distracted society from the recognition of people with disabilities as people first, with the same needs and aspirations as anyone else. Rethinking the extent to which the barriers to inclusion are truly a result of different functioning, leads to recognition of people with disabilities as rights-bearers, rather than as people in need of charity or welfare. An attitude to people with disabilities which conflates impairment with personhood is itself a barrier to inclusion.[4]

One way of assessing the extent to which people with disabilities are thought of as equal members of society is by paying attention to the portrayal of disabilities in the media.[5] If people with disabilities are constantly positioned as villains and the epitome of evil, it can be assumed that fear of disability is extant. If people with disabilities are seen as super-human, like Helen Keller perpetually discovering language at the water-tank, rather than ordinary people sharing the struggle for an ordinary life, we can assume that people with disabilities continue to hold outsider status.[6] If disability is shown as personal tragedy, overcome by heroes who are always able to walk away from their wheelchairs by the end of the story, it can be assumed that disabilities can be overcome with the right attitude. These sorts of images both mould and reflect the values of a society and stand in the way of the true inclusion.

The second dimension to the inclusion principle is access. This builds on the social model of disability which locates disability outside the individual. The social model seeks to identify and eliminate restrictions which prevent inclusion. Barriers may take the form of stairs or the way in which a building is constructed, affecting, for example those using wheelchairs; or it may be the way in which information is communicated, where small print or complex language may exclude those with vision impairments or intellectual disabilities respectively. It is the basic arrangements of the society which will often need to be reorganised. While individuals can locate and complain about structural impediments, it is the responsibility of the society (not just the government, but individual citizens such as shopkeepers, bartenders or headmasters) to dismantle or remove barriers. Most often this will require the taking of active steps, for the *status quo* is designed in the interest of dominant groups. Unless there is an attitude which empowers rather than represses people with disabilities, access will not be achievable.

Accessibility makes participation possible. Without access, people with disabilities are excluded from the life which those without disability take for granted. Simple things like catching a bus, using the local library, doing the shopping, seeing a film or going to church can be too difficult for a person with a disability. And if the person has been denied the right to an appropriate education, her chances in the labour market and her ability to relate to peers may be curtailed. Equally, being denied the right to participate in the labour market will not only have an impact on an individual’s sense of well being, but will also limit his or her financial ability to take advantage of the social, leisure, cultural or religious activities available in the community in which they live. Access to

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[3] On the various approaches to disability see M Jones & LAB Marks (2001) “Law and People with Disabilities” *International Encyclopaedia of the Social and Behavioural Sciences*; Title 3.8.133; Discipline: Law

[4] See, for example, M Rioux (2003) “On Second Thought: Constructing Knowledge, Law, Disability & Inequality”in S Herr, L Gostin & H Koh *The Human Rights of People with Intellectual Disabilities* OUP

[5] See generally, R G Thomson (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture & Literature* Columbia U Press; S Crutchfield & M Epstein (eds) *Points of Contact* 2000 U Michigan Press

[6] Liz Crow (2000) “Helen Keller: Rethinking the Problematic Icon” 15 *Disability & Society* 845 - 859

participation in all aspects of the social, cultural and economic life of the society is a requirement of the human rights principle of inclusion.[7]

Ensuring access does not, by itself, guarantee inclusion. Rather, a third dimension to inclusion is required. For meaningful engagement to occur, it will often be necessary to facilitate the inclusion of people with disabilities. This may take the form of providing equipment or medicine. It may be that for a particular individual to participate, a support person will be required. More often it will involve an alternate strategy to achieve an end. Examples of this are a modified curriculum for a person with an intellectual disability; audio format for those for whom reading is difficult; captioning of visual media for the hearing impaired; and audio cues at pedestrian crossings. Not only is facilitation needed at a macro level, but individuals may need accommodation in all sorts of ways to ensure the highest level of independence and functioning. Where, for example, an individual is unable to button shirts or tie shoelaces, it should be easy enough to provide clothes with zips and shoes with velcro or buckles, even if this requires a deviation from a specified uniform. The cost to an organization is low; and the gain to the individual immense. Facilitation of this sort makes a massive difference to the impact of disability and to the autonomy of the individual.

It is not only people with disabilities who benefit from facilitation when accessing the resources available in the society in which they live. Multicultural societies have embraced the need for interpreters and multilingual publications, recognising that without these the participation of people from non-English speaking backgrounds will be limited and their rights to social goods such as a fair trial may become meaningless. Equally, the provision of childcare is designed to facilitate women in the workforce and the provision of maternity leave is designed to accommodate working mothers. Facilitating people with disabilities changes the terms by which interaction with others is possible, and discounts the impact of disability on ordinary existence.

Maimonides, a 12th century Jewish thinker, saw the virtue of inclusion. In his discussion of the Jewish law of *tzedaka*, often translated as ‘charity’ but actually meaning ‘justice,’ The highest and ideal form of *tzedaka* involves anonymously providing a poor person with the means by which to become independent.[8] It is a just society which recognises that providing support to enable independence is beneficial not just to the individual but to the society as a whole. Further, it should be recognised that establishing the right to be facilitated is a matter of self-interest as well as a means of supporting people with disabilities - statistically there is a very high chance that any given person or a close relative will become disabled at some point in their lives.[9]

Inclusion as a Human Right

Although human rights are a serious business, the analogies generally used to explain their function come from the world of game playing. Richard Dworkin, in his seminal account of the modern liberal conception of rights, describes rights as trump cards.[10] When someone has a trump, all the other players must defer to the power of the trump. When someone has a right, it puts an end to argument or discussion about the best decision in the case at hand. On this basis, having the right to inclusion gives you an ethical trump card, which will allow you to direct the outcome of arguments of principle. This is the difference, according to Dworkin, between rights in the strong

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[7] On the importance of accessability for participation see I M Young (1990) *Justice and the Politics of Difference* Princeton U Press; Yeatman A “What Can Disability Tell Us about Participation” in Jones M & Marks LAB (2000) *Explorations on Law & Disability in* Australia Federation Press 181-200

[8] On Maimonides’ eight levels of *tzedaka*, see Rabbi Joseph Telushkin (2009) *A Code of Jewish Ethics (Vol2 Love Your Neighbour as Yourself) at* 187-191. For discussion of the issue of tzedaka in Jewish Law and practice, see Telushkin 156-259

[9] LA Basser (2008) “Disentangling Disability and Health” in B Bennett, T Carney & I Karpin *The Brave New World of Health* Federation Press 218-236

[10] Dworkin, R (1990) *Taking Rights Seriously* Duckworth.

sense and the weak sense of rights. A strong claim is a claim which promotes the fundamental requirement of rights: that is, the treatment of all people with equal concern and respect.[11]

An alternative view of rights, developed by feminist legal scholars and critical race theorists, sees rights as providing entry into the discourse of society; to help to define the boundaries between people, to structure relationships.[12] Minow argues that rights, "are calls for communal dialogue: the language we use to try to persuade others to let us win this round".[13] From this perspective, rights are the cards we play with, and having a claim to rights involves being welcome at the card table. Rights are matters to be negotiated. Being dealt a hand means that your voice can be heard and your perspective considered.

This second account of rights gives greater meaning to the concept of inclusion as a right. By being allowed to be participants in the discourse of rights we become entitled to "a basic equality among participants as participants".[14] Allowing people with disabilities to be players is a crucial prerequisite to inclusion. Disagreements are inevitable when there are 52 cards in play, but instead of the result being a win/lose situation, resolution is reached by communal discourse directed towards fundamental values.

The language used within social discourse can itself be indicative of the true level of commitment to the rights of people with disabilities. At one end of the spectrum is 'tolerance' – where the society demonstrates a willingness to put up with presence of difference, but not to embrace it. When we are prepared to tolerate people with disabilities we do not object to their presence as viewers of the game, but we do not really want them to play. Beyond tolerance is the idea of 'acceptance' – where people with disabilities are welcomed to the table and allowed to play. However, acceptance does not require an alteration of the rules or an adjustment of the cards. For inclusion to occur, it is necessary to move beyond toleration and acceptance. Including others requires a willingness to facilitate or accommodate difference – a willingness to make changes to the game, to the structural requirements of the game, to the playing pieces or even to the criteria for winning. Inclusion involves the amelioration of difference until it becomes irrelevant to the chances of success.

An example of the use of language with respect to the educational opportunities for children with disabilities indicates the importance of demanding inclusion. When the objective of education is 'mainstreaming', there is no demand for equality. Rather, children with disabilities are tolerated on the same campus as others, and share some of the school's facilities. However, segregation in separate units or separate classes is not seen as contrary to providing rights. Children with disabilities are present in the school community, but not really a part of it. On the other hand, 'integration' of children with disabilities is evidence of acceptance. When children with disabilities are integrated into the classroom, they become part of the class and part of the learning community. However, as the Canadian Supreme Court said in *Eldridge*, integration is, "conditional upon their emulation of able-bodied norms".[15] If the child cannot operate firmly within the *status quo*, the child will simply miss out on the activity. It is the children with disabilities who must adapt themselves as well as they can, and who must participate as much as they are able.

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[11] Dworkin, R (1990) *Taking Rights Seriously* Duckworth at 184ff

[12] Minow, M (1990) *Making All the Difference: Inclusion, Exclusion & American Law* Cornell University Press; Patricia Williams (1993) *The Alchemy of Race and Rights Virago;* M Jones (1996) "Balancing Competing Human Rights" Communications Law Centre *Proceedings of Conference on Free Speech in Australia* 10th September 1996, 45-49

[13] Minow, M (1990) *Making All the Difference: Inclusion, Exclusion & American Law* Cornell University Press at 295.

[14] Minow, M (1990) *Making All the Difference: Inclusion, Exclusion & American Law* Cornell University Press at 297.

[15] *Eldridge v British Columbia* (1997) SCJ No 86 at 56

When it is 'inclusion', rather than 'mainstreaming' or 'integration', which is sought, much greater demands are being made of the system. When a child is included, the barriers to participation will be removed and active steps will be taken to ensure the child's social and academic well-being. It is the classroom and the learning processes that will have to be adapted to allow for meaningful participation and to allow the child the same educational opportunities as provided for other students.[16] As such, inclusion requires mitigation of the effects of difference.

Human rights, then, require more than the recognition of the equal worth of all people and the commitment to treating everyone with dignity and respect. Human rights are social tools for the achievement of a just society. Excluding some people is not only disrespectful; it involves holding some people to be less equal than others. Inclusion is the operational principle for ensuring that all people can be meaningfully involved in society and that all people can meaningfully engage in both the benefits and burdens of citizenship.

Social Exclusion & Social Inclusion

The discourse of 'social exclusion' and 'social inclusion' has hijacked the public policy debate about the idea of inclusion in Europe, Canada and Australia. While this debate rarely revolves around the rights or needs of people with disabilities, the implications of a social inclusion perspective are potentially wide-ranging and have the potential to be supportive of the rights of people with disabilities. Walker & Walker explain that social exclusion

> … refers to the dynamic process of being shut out, fully or partially, from any of the social, economic, political or cultural systems which determine the social integration of a person in society. Social exclusion may therefore be seen as the denial (non-realization) of the civil, political or social rights of citizenship.[17]

Similarly, Teague & Wilson comment that social exclusion in not just a description of inequality, but

> … a set of *processes*, including within the labour market and the welfare system, by which individuals, households, communities or even whole social groups are pushed towards or kept within the margins of society It encompasses not only material deprivation but more broadly the denial of opportunities to participate fully in social life. It is associated with stigmatisation and stereotyping …[18]

The term social exclusion was coined in France in 1974 in response to growing poverty and social unrest, not to describe the experience of people with disabilities.[19] The idea of social inclusion took hold somewhat later, emerging as a core element of the Blair government's 'Third Way'.[20] Because from the outset the terms lacked conceptual clarity,[21] the language of social inclusion and exclusion has been used to justify a range of conflicting ideological positions. While some have attempted to distinguish social inclusion from social exclusion, arguing that the difference depends on the respective attribution of responsibility for the marginalisation to the state or to the members

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[16] Basser LA & Jones M (2002) "Fostering Inclusive Societal Values through Law" (2002) 10 *International Journal of Children's Rights* 371-402

[17] Walker, A & Walker, C (eds) (1997) *Britain Divided: The Growth of Social Exclusion in the 1980s & 1990s* CPAG, London, cited by Saloojee A (2003) "Social Inclusion, Anti-Racism & Democratic Citizenship" Laidlaw Foundation Working Paper Series at 11. Saloojee (at 4) considers that exclusion describes the process by which dominant group are able to secure the greater share of society's valued goods to use their advantages to reinforce their control over rights, opportunities and privileges in society.

[18] Teague, P & Wilson, R (1995) "Towards an inclusive society" in Democratic Dialogue *Social Exclusion, Social Inclusion* Report No. 2 Belfast at 1: <http://cain.ulst.ac.uk/dd/report2/report2m.htm#inclusive>

[19] See Saloojee A (2003) "Social Inclusion, Anti-Racism & Democratic Citizenship" Laidlaw Foundation Working Paper Series at 1

[20] Giddens A (1998) *The Third Way: The Renewal of Social Democracy* Polity Press; Giddens A (2000) *The Third Wayand its Critics* Polity Press; H Collins (2003)"Discrimination, Equality & Social Inclusion" 66 *Modern Law Review* 15-43

[21] H Collins (2003)"Discrimination, Equality & Social Inclusion" 66 *Modern Law Review* 15-43

of the outsider group, this does not hold.[22] It is generally accepted that social exclusion and social inclusion involve the complex, multifaceted interaction between those at the centre and those at the margins. Beyond this, however, little can be predicted about the content of a claim of concern about those experiencing social exclusion. This is because the language of social exclusion has been co-opted by all sides of the political divide, with each group colouring the notion of social exclusion with its own perspective.

Levitas has characterised the alternative political usages of the terminology of social exclusion and social inclusion as a redistributive discourse [RED],[23] a social integrationist discourse [SID],[24] and a moral underclass discourse [MUD].[25] Those adopting RED consider the major barrier to participation to be poverty, which includes both lack of money and lack of financial capacity.[26] The solution proffered by RED is to increase welfare to reduce poverty and to deal with discriminatory and exclusionary practices. This perspective has something to offe r people with disabilities.

While RED lays responsibility for dealing with exclusion firmly in the hands of the state, SID and MUD cast marginalised individuals in a more central role.[27] SID is concerned with the exclusion from paid work and the need for the moral integration of those outside the labour market. Its concerns are economic efficiency & social cohesion, which it considers can only be legitimately achieved through paid work. From this perspective, serious attention needs to be paid to problems created by those outside the paid workforce, and coercive measures may be needed to bring these outsiders in. MUD, on the other hand, considers the problem of social exclusion to be the lack of moral responsibility on the part of the marginalised underclass, which is compounded by learnt dependency. By focusing on the behaviour of the poor, and the danger to social order posed by outsider groups - such as unemployed, potentially criminal, young men; single parents, especially unmarried mothers; and children who truant from school - the MUD reduces social exclusion and social inclusion to an excuse for social control.

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[22] See Mitchell & Shillington "Poverty, Inequality & Social Inclusion" in *Perspectives on Social Inclusion* Laidlaw Foundation Working Paper Series *passim*; Saloojee A (2003) "Social Inclusion, Anti-Racism & Democratic Citizenship" Laidlaw Foundation Working Paper Series at 13 sees social inclusion as a radical response to exclusion. The contrasting position is held by Teague & Wilson *ibid* who argue social exclusion is the responsibility of the wider society. Levitas demonstrates the alternative positions held in the name of social inclusion and social exclusion.

[23] RED was commonplace in critical social policy throughout the 1980s and 1990s, and is consistent with the right to inclusion. The redistributive discourse considers social exclusion to be a consequence of poverty. As such, increasing welfare to reduce poverty is crucial. Equally, reducing discriminatory and exclusionary practices that may be causes of poverty (which includes the inability to participate in the customary life of society) are central to RED. This discourse of social exclusion focuses on processes which produce inequality and implies a, "radical reduction of inequalities & a redistribution of resources and power." Levitas, R (1998) *The Inclusive Society? Social Exclusion & the New Labour* Macmillan, London at 14.

[24] SID obscures the underlying causes of inequality and exclusion and undermines the legitimacy of non-participation in paid work. This casts moral aspersions about the value of those who stay home as carers (whether as parents or as supporting people with disabilities) and about the reality that some people may not be able to work (for example as a result of complex multiple disabilities, psychiatric disabilities or chronic illness). Rather than empower those excluded from the workplace by providing alternative means of inclusion, SID de-legitimates anybody outside the labour market.

[25] Levitas, R (1998) *The Inclusive Society? Social Exclusion & the New Labour* Macmillan, London; Levitas, R (2003) "The Idea of Social Inclusion" Social Inclusion Research Conference

[26] Sen argues that this is only a new approach to the extent that earlier discourses of poverty often lacked the element of capacity, which he has argued for many years is central to a sophisticated analysis of poverty. Amartya Sen (2000) *Social Exclusion: Concept, Application & Scrutiny Social Development* Papers No 1 Office of Environment & Social Development Asian Development Bank, 1-6

[27] According to SID, the responsibility for solving the problem lies both with the state, which must use a carrot/stick approach to weaning people off welfare, and the currently unemployed individuals who must change their attitude and get to work. According to MUD, social benefits are the cause of dependency and the state needs to regulate the behavior of those who lack moral character. MUD is a language of moralism and moral panic, which seeks mainstreaming through the labour market.

Salooji suggests an alternative characterization of the different uses of the language of social exclusion and social inclusion.[28] He distinguishes between strong and weak positions on social exclusion/inclusion. The weak version is concerned with the integration of the excluded into society, which it claims will come about when the individuals involved change their behaviour and take greater responsibility for their own well-being. The focus of this weak idea of social exclusion is on individuals entering the paid workforce, which is to be encouraged through welfare reform. This notion of social exclusion is considers that individuals will not only gain the economic advantages of a higher income when they join the paid workforce, but will also gain the concomitant benefits of self-esteem and of social engagement. Voluntary work may also provide benefits to those outside the paid workforce, but if that work is domestic labour or childrearing responsibilities (usually falling upon women) the benefits of participation will not be achieved. This weak construct of social exclusion and social inclusion is similar to Levinas' social integrationist/moral underclass discourse, and poses a threat to the human rights of people with disabilities. It assumes that opportunities are available, if only people would take advantage of them. It is blind to the reality of structural impediments to participation and legitimises the reduction of benefits to an unviable level for those who are dependent on them.

Salooji's strong version of social exclusion/social inclusion is more useful both as a description of the experience of people with disabilities and as a transformative tool. Like Levinas' RED, the strong version of social exclusion and social inclusion focuses on the relationship between those who are excluded and those responsible for their exclusion. This approach disentangles the various current and historical processes that reproduce oppression, discrimination and exclusion. According to Salooji, the:

> [s]trong approaches to social inclusion discourse therefore are intimately concerned with rights, citizenship and restructured relations between radicalized communities and the institutions of the dominant society. The focus is on valued recognition and valued participation by those excluded from full participation in society and the benefits of society.[29]

Because it is open to a policy analyst, scholar or politician to adopt a weak or strong position, or to use the language of social exclusion/inclusion as a transformative principle or a crass ideological tool, it is essential to understand that adoption of the language of social exclusion or social inclusion does not guarantee a relationship with the human rights principle of inclusion. Nonetheless, the literature on social exclusion and social inclusion resonates with the experience of people with disabilities. Equally, the strong versions of social inclusion discourse parallel the analysis of the rights of people with disabilities developed by disability scholars. In this respect, social exclusion discourse discloses the existence of structural constraints located in the very fabric of society. It points to the lack of access to social goods; lack of resources which prevents individuals becoming effective, contributing members of society; and to the reality that members of marginalised groups are not recognised as full and equal participants. Social inclusion offers a new approach to inequality and injustice,[30] critiques hierarchies of oppression and promotes a transformative agenda. To this extent social exclusion/inclusion be able to be co-opted to promote the rights of people with disabilities.

Two issues raised in the context of social exclusion/social inclusion that bear further comment are poverty and social well-being/solidarity. Of the world's 650 million people with disabilities, 80% live in developing countries.[31] Both in those societies and in the north, people with disabilities are disproportionally among the poorest members of the society. Amartya Sen argues that poverty does not only relate to the level of income or the money available, but also relates to the capability

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[28] Saloojee A (2003) "Social Inclusion, Anti-Racism & Democratic Citizenship" Laidlaw Foundation Working Paper Series at 1-2

[29] Saloojee A (2003) "Social Inclusion, Anti-Racism & Democratic Citizenship" Laidlaw Foundation Working Paper Series at 1

[30] Collins argues that social inclusion may provide a means of defending anti-discrimination laws and explaining deviations from the rules of formal equality. H Collins (2003)"Discrimination, Equality & Social Inclusion" 66 *Modern Law Review* 15-43 *passim*

[31] UN Enable *Fact Sheet on Persons with Disabilities* http://www.un.org/disabilities/default.asp?id=18

that a person has to use that money to achieve full participation in society.[32] He argues that there are two ways in which poverty handicaps people with disabilities: an 'earning handicap' and 'conversion handicap'. Attention needs to be paid to 'earning handicap' because people with disabilities may find it harder to get a job or to retain it, and may receive lower compensation for the work they undertake. Anti-discrimination law may be useful in addressing these problems, and the constituents of inclusion – attitude, access and facilitation – will need to come into play. However, people with disabilities are not only disadvantaged in terms of income-producing capacity. The ability of people with disabilities to convert money into whatever is required for good living is limited by the 'conversion handicap'. A person with a disability may need more income to do the same things as someone without a disability. For example, to move or hear, a person with a disability may require assistance, and whether this takes the form of a wheelchair, an hearing aid, an interpreter or personal support, this may cost a great deal of money to any given individual. As a result:

> [w]ith the same level of income a disabled person may be able to do far fewer things, and may be seriously deprived in terms of the capabilities that he or she has reason to value. For the same reason for which disability makes it harder to *earn* an income, disability also makes it harder to *convert* income into the freedom to live well.[33]

The implications of this are significant. If Sen is correct in finding that in the UK only a quarter of the poverty of people with disabilities can be attributed to 'income handicap' and three-quarters to 'conversion handicap', then any assessment of social supports required to achieve equality for people with disabilities must not only look to the generalised cost of living, but must focus on the cost of living with a disability. The personal cost of disability will also vary depending on the degree to which institutions and the infrastructure of the state are designed to facilitate the inclusion of people with disabilities.

Further, the radical discourse of social exclusion/ social inclusion accepts that there is more to exclusion than poverty. Being excluded is also about social well-being, which includes, in addition to the basic provision of food and shelter, the opportunities to participate in the life of the society in a meaningful way. Access to non-material goods such as work and self-esteem, require that the social organisation of society is such that these are potentially available to all. Collins argues that the emphasis on the distribution of non-material goods derives from the fundamental objective of social inclusion, that is, social solidarity.

> Although we have observed that social inclusion shares with equality a concern with the distributive allocations to groups and individuals in a society, its more fundamental objective is the outcome of social cohesion. Social inclusion is a theory of how society can be integrated and harmonious. At its simplest, the theory is that if everyone participates fully in society, they are less likely to become alienated from the community and will conform to its social rules and laws. Social inclusion fosters social cohesion or, to use an older concept, solidarity. The outcome sought by policies of social inclusion is therefore not merely justice for individuals but also a stable social order.[34]

There is no doubt that one consequence of exclusion from society is alienation, and that addressing exclusion may lead to meaningful engagement in society. The right to inclusion is about the right to be a full member of society. This means that people with disabilities are entitled to both the material and non-material goods that make participation possible. Each of the three dimensions of inclusion is at stake. The most critical of the elements; attitude, is not a material good. While material goods are important, people with disabilities cannot be included without the provision of non-material good. Meaningful engagement and valued recognition depend on a social commitment to respond to all aspects of exclusion.

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[32] Amartya Sen (2000) *Social Exclusion: Concept, Application & Scrutiny Social Development* Papers No 1 Office of Environment & Social Development Asian Development Bank; Amartya Sen (1992) *Inequality Reexamined* Russell Sage Foundation

[33] Sen, A. K. (2004). "Disability and Justice". Disability and Inclusive Development Conference, Keynote Speech, World Bank. Washington, D.C. Processed. Page 3

[34] Collins H (2003) "Discrimination, Equality & Social Inclusion" 66 *Modern Law Review* 15 at 23.

A Checklist Approach to Inclusion

One practical approach to the inclusion principle is to use a checklist to ensure that all matters have been taken into account. Assuming that there is a commitment to achieve substantive equality in the operation of policy, a process of thought that makes specific reference to the differential impact of policy and to the complex, diverse structure of needs and interests represented in the community, will be crucial. When it comes to the checklist of members of the community for whom a social policy is being devised, the checklist would provide the challenge of addressing the full range of stakeholders in the policy being developed. In particular, the list would commonly involve the following:

Step 1: including the whole community

- Have you included the needs of women as well as men; children as well as adults?
- How will the policy impact on people whose sexual identity is not heterosexual?
- Have you taken into account the full diversity of cultural and religious groups that are part of the community?
- Have you considered the impact upon people from diverse ethnic and racial groups?
- Have you considered the impact of the policy on the homeless and the jobless?
- Have you taken into account the position of those living in rural as well as urban areas?
- Have you taken into account the position of migrant workers and their families?
- Have you considered the impact upon refugees and other non-citizens?
- Have you taken into account the effect of the policy on people with disabilities?

The inclusive attitude necessarily extends beyond disability, and the models used to include other groups of people will have a flow-on effect on people with disabilities. However, when it comes to disability it is not sufficient to consider people with disabilities as a class, for the needs and impact upon different people with disabilities varies with the type and degree of disability. It is therefore necessary to take a further step.

Step 2: Ensuring Inclusion for all People with Disabilities

- Are *all* people with disabilities going to be able to share the benefit of the policy?
- Does the policy impose physical structures that exclude people with mobility disabilities?
- Is accommodation made for people with visual or hearing impairments?
- Does the policy include a means with which to facilitate the inclusion with intellectual disabilities?
- Will the policy take into account the periodic absenses of those with chronic illness or the instability of many people with psychiatric disabilities?
- What differential impact, costs or benefits will confront people with disabilities in the implementation of the policy?
- Is it taken for granted that that people with disabilities will be able to equally benefit from the policy, or have steps been taken to ensure inclusion?

The question must always be: can the policy be adapted to ameliorate the differential impact on disability and/or other “outsider” status? Taking into account the needs and experiences of people with disabilities goes a long way towards developing an inclusive society. It requires lateral thinking – going outside the box of the media-screened world – that may result in creative solutions to newly understood problems.

A third checklist must be added to the others if we are to assess the inclusive quality of the social structure or of social institutions. This list will involve the deconstruction of the issue under consideration, such that the minutiae of policy can be checked against the community or disability checklist. As this third list will be specific to the issue under examination it is, perhaps, easiest to demonstrate the application of the checklist approach by working through two example areas.

a) The Right to Vote

The right to vote is the most basic of all political rights, and having the right to vote is a mark of membership of a community.[35] Those who are entitled to vote are those who matter to the society, whose opinion is valued, and whose judgement is respected. History has shown that even where there are claims of ‘universal sufferage’, substantial groups within the society may be denied the vote. Women, indigenous peoples and the poor or indigent are the most likely people to be excluded from political participation.

Voting and political participation are not only intrinsically valuable as aspects of freedom, they are also of instrumental effect. Those engaged in governing tend to take notice of and listen to those whose opinion can affect their prospects of re-election and their access to power. It has been suggested that the difference between places in Europe where migrant workers riot, and those where there is a far greater degree of harmony (for example, between France and Germany) turns on the fact that in the former situation politicians gain no benefit from taking the needs of migrant workers into account. Equally, right wing/ racist groups have no fear of defeat at the polls.[36]

In democracies, involvement in the political process through participation in elections is considered the fundamental right of all citizens. However, it is far more complex an issue than the physical act of casting a ballot.

The minimum content of the right to voting includes:

- The right to participate in the election;
- The right to register to vote (where such a system exists);
- Access to information about the electoral system, including how, when & where to vote;
- Access to information about competing policies, platforms or ideas of the respective candidates and/or political parties;
- The right to participate in public debate about the respective ideas being presented by candidates and/or political parties;
- The right for the vote to be by secret ballot; and
- The right to stand as a candidate and/or to hold political office.

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[35] On human rights and the right to vote, see Jones M “The Right to Vote and Participate in Political Processes” *Human Rights*, The Laws of Australia, Law Book Co. (1995) 11-29; Gaze E & Jones 4 *Law, Liberty and Australian Democracy* (1990) Law Book Company at 73-114

[36] Amartya Sen (2000) “Other People” 111 *Proceedings of the British Academy* 11

The ability to have a political voice is underscored, as Sen points out,[37] by the concomitant transparency of information. Political freedom entails not only the freedom to be heard, but also the freedom to demand information. Teasing out the elements of the right to vote allows us to recognise the points of the process which may exclude people with disabilities, and to establish what needs to be done to ensure inclusion.

The checklist begins with the question: does the law specifically exclude any people with disabilities from participating in elections? For example, in some jurisdictions people with psychiatric disabilities and people with intellectual disabilities are specifically denied the right to vote. People with other sorts of disabilities may also find themselves exxcluded by law. This is clearly unacceptable.

Once all people with disabilities are granted the right to vote, the checklist continues:

- Are any people with disabilities excluded from participating because they are unable to access voting in the form it is presented? For example, are voting places physically accessable? Are there alternative ways of marking a ballot paper? (Is voting predicated on the ability to write or read?) Does voting require standing in a queue for an extensive period of time?

- Similarly, if voter registration is required, are there terms and conditions which some people are unable to meet because of their disabilities? Does voter registration require, for example, complex language skills or the ability speak?

- Do people with disabilities have access to information about the electoral system, including how, when & where to vote? Is electoral information available in accessible formats (braille, big print, audio) Does the informtion take the form tht it is intelligible to people with intellectual disabilities?

- Can people with disabilities accessing and participate in public debate about the respective ideas being presented by candidates and/or political parties? (Are there issues of physical access? Are interpreters available?

- Even where an aid is needed, are people with disabilities provided with the means to secretly record their votes? Is it possible for all people to enter their votes secretly?

- Are some people denied the right to be candidates in elections or to hold political office?

For people with disabilities, information about disability policies, about spending, about distribution of wealth and about the attitudes of candidates to disability is crucial to the exercise of political power. Unless access to the electoral process is guaranteed, people with disabilities will continue to be marginalised. Once it is known that people with disabilities have a political voice, disability will become an issue are of concern to politicians - voters count; non-voters don't.

b) The Right to Education

Education is another crucial area for inclusion. The language of inclusion is often used to describe the means of ensuring meaningful participation in the classroom. However, to fully implement the right of inclusion, every aspect of education must be considered.

The right to education has been said to consist of four elements: availability (to ensure no-one is excluded); accessibility (in terms of non-discrimination, physical accessibility and financial a accessibility); acceptability (demonstrating a commitment to human rights); and adaptability

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[37] Amartya Sen (2000) *Social Exclusion: Concept, Application & Scrutiny Social Development* Papers No 1 Office of Environment & Social Development Asian Development Bank at 40

(meeting the needs of all learners).[38] There are four cornerstones of the right to education, and each of the elements of the right to education must be applied in each area: the composition of the school community; the classroom and the curriculum; the concern of the teacher; and the values of the education system. This means that attention must be paid to whether the school community is inclusive in the sense that the full range of traditionally excluded people are given a place and a voice. The classroom must be inclusive in its physical manifestation and in the way learning is arranged. The curriculum must be suitable, but also must give recognition to the reality of diversity. The teachers must demonstrate an inclusive attitude in both their teaching methods and in their classroom management.

Considerable work has been done on the right to education, particularly with respect to physical inclusion and curricula adaptability. However, the full picture is often out of focus. One area, for example, has received relatively scant attention. This is inclusion in the curriculum in the sense that people with disabilities are portrayed as ordinary people entitled to valued recognition. Perhaps the simplest response to the latter is to include books with characters with disabilities in the curriculum. Examples of these are two Australian children's novels, *Jodie's Journey* by Colin Thiele[39] and *Blabber Mouth* by Maurice Glietzman[40]. *Jodie's Journey* is about a girl who develops juvenile arthritis and has to come to terms with being unable to compete in show jumping. *Blabber Mouth* deals with a mute child, whose problems are not with her inability to speak but her father who intervenes inappropriately. Each of these are strong characters and real people dealing with real problems facing children generally.

While it is not realistic to assume that every school can make provision for every abstracted child with a disability, there are some general and specific accommodations that can be expected. When a facility is being built, there is no reason why it cannot be designed with the needs of mobility-impaired people in mind. Especially in developing countries, but also elsewhere, children are excluded from school due to building design. Adapting existing buildings is neither difficult nor expensive. It may be that the position of a particular classroom may need to be changed or the library relocated. The cost involved in measures of this sort cannot be compared to the cost of exclusion from education. Similarly, adapting the difficulty of teaching material to meet the needs of different groups of learners is simply good teaching practice. With the use of computers, it is easy to produce material in large print or to modify a worksheet. The main issue is the willingness of the teacher, school and community to respect the rights of all children.

Because success in education is crucial to success in other areas of life, failure to provide adequate appropriate education to all children is tantamount to perpetual exclusion. It is not enough for children to be physically present, although this is a good start. Children with disabilities must be meaningfully engaged in the full range of benefits available through education. The relevant questions with respect to education are:

- Is any child excluded from school (whether due to financial, physical or intellectual constraints)?
- Is any child excluded from any aspect of school-life (including learning, assemblies, excursions, playtime, sport and extra-curricula activities)?
- Is the teaching programme relevant to all learners?
- Are the education system, the school and the teacher committed to inclusion?
- Has teacher training taught flexibility to respond to diversity amongst the student body?

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[38] Katerina Tomasevski (2006) *Human Rights Obligations in Education: The 4-A Scheme*, Wolf Legal Publisher; Katerina Tomasevski (2003) *The Right to Education* Report submitted by the Special Rapporteur, Katarina Tomasevski, U.N. Doc. E/CN.4/2004/45, 26 December 2003

[39] Colin Thiele (1988) *Jodie's Journey* Walter McVitty Books

[40] Maurice Glietzman *Blabber Mouth* 1992 Pan Macmillan

- Are the teaching materials accessible to all?
- Is the classroom designed with the needs of all learners in mind?
- Are all children facilitated in such a way that the learning is meaningful?
- If support is required for a student to be included, is this available? (Support may take the form of personal assistance, modification of materials or equipment)
- Is support or assistance designed to enhance the valued recognition of the child?

The checklist approach to inclusion offers practical guidance in ensuring that the educational needs of all children are met. While this discussion has focused on questions relevant to primary school, the issues are also pertinent to pre-school, secondary school, tertiary institutions and adult education programmes. Wherever educational opportunities exist, it must be open to all members of the community to participate fully. It is particularly important to ensure access to participate in vocational training programmes, as the inability to participate in work-related learning affects the work and earning potential of the individual. Given the centrality of education to every aspect of life, and the correlation between substandard or no education and poverty, ensuring that people with disabilities have equal opportunities for education is crucial. To be included in education, each of the three dimensions of inclusion must be present. There must be a commitment to equality and an inclusive attitude; there must be access, and there must be facilitation. Only then will the rights of people with disabilities be respected.

Inclusion and the Law

The *International Convention on the Rights of Persons with Disabilities [Disability Convention]*[41], which clarifies the position of people with disabilities in international law, was adopted by the United Nations on 13 December 2006 and entered into force on 3 May 2008. The extent to which the treaty is law in any country will depend on whether that state has ratified the convention, and then, where required, if it has been incorporated into the law of the country.[42] As at the end of 2009, 143 states had signed the Convention and it had been ratified by 76 nations. Even where the treaty has not become part of the law of a country, the principles enunciated and the rights protected are nonetheless clear statements of support for people with disabilities. For the present purpose, it is significant that 2 of the 8 General Principles governing the operation of the *Disability Convention*, principles encoding the most basic requirements necessary for the rights of people with disabilities to be met, are concerned with inclusion. These general principles, listed in Article 3 of the Convention, are: (c) full and effective participation and inclusion in society; and (f) accessibility. Article 9, which deals with accessibility, outlines steps that parties must take if they are to accord human rights to people with disabilities. Article 9(1) reads:

> To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

Article 19, relating to “living independently and being included in the community”, takes this one step further:

> States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and *shall take effective and*

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[41] *International Convention on the Rights of Persons with Disabilities*

[42] On international law and human rights, see Smith RKM (2007) *International Human Rights* Routledge

> *appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community*... (emphasis added)

A number of other articles in the *Disability Convention* are relevant to the principle of inclusion. These include: Article 8 - Awareness-raising; Article 13 - Access to justice; Article 20 - Personal mobility; Article 24 – Education; Article 25 – Health Article; 27 - Work and employment; Article 29 - Participation in political and public life; and Article 30 - Participation in cultural life, recreation, leisure and sport.

The *Disability Convention* does not replace other relevant international law, but sits alongside the other human rights treaties and other international instruments. It is important to understand that state obligations to accord human rights to people with disabilities do not begin or end with the *Disability Convention*. There is a great deal of other international law specifically relevent to people with disabilities, and there is a substantial body of human rights law applicable to people with disabilities. The *Disability Convention* updates some of that law and clarifies the position of people with disabilities with respect to human rights generally. Nonetheless, both guidance and leverage can be gained for people with disabilities though knowledge of the law generally, and can be used strategically in any campaign for inclusion.

With respect to access and participation of people with disabilities, the most significant instrument developed prior to the *Disability Convention* is the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules)*.[43] Building on the *World Programme of Action Concerning Disabled Persons,*[44] the *Standard Rules* emphasise that people with disabilities have the right to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. The *World Programme of Action* had defined equalisation of opportunities to mean:

> the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.[45]

The *Standard Rules* specify that general awareness of the rights of people with disabilities, provision of appropriate medical care, rehabilitation and support services are prerequisites of access and participation. States are called upon to recognise the importance of accessibility to the process of equalisation of opportunity. Specific areas of life are then targeted as focal points for beginning the process of providing full rights to people with disabilities. In particular, there are rules relating to access to the physical environment, access to education, and access to employment. States are held to be responsible for, among other things, the provision of social security and income maintenance, and to ensure equality with respect to family life, culture, religion, sport and recreation.

While equalisation of opportunity does not specifically cover the third dimension of inclusion, the *Standard Rules* do make reference to the need for facilitation of people with disabilities if the access provided is to be successful. Rule 4 requires states to provide equipment and assistive devices, personal assistance and interpreter services. Acknowledging the potential financial barriers to access, Rule 4 also specifies that assistive devices should be provided by the state free of charge or at a very low cost. With respect to inclusion in education, some aspects of accommodation requirements are demanded of states, which are to provide appropriate support services as well as access.[46] Equally in the context of employment, the *Standard Rules* insist that states should adopt measures to design and adapt the workplace. States should also play a leading role in the development and use of technical means of making the arts accessible to all.

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[43] United Nations General Assembly Resolution 48/96, adopted at the 48th session of the General Assembly on 20 December 1993.

[44] United Nations General Assembly Resolution 37/52 (1982).

[45] Ibid at Para 12.

[46] *Standard Rules*, Rule 6 Para 2.

With respect to the attitudinal and non-discriminatory dimension of inclusion, many instruments proclaim that *all* people are equal[47] and that the specific rights provided for by the instrument shall apply without discrimination of any kind. As such, the International Bill of Rights – comprising the *Universal Declaration of Human Rights* [UDHR], the *International Covenant on Civil and Political Rights* [ICCPR] and the *International Covenant on Economic, Social and Cultural Rights* [ICSECR] – are all applicable to people with disabilities, even in the absence of reference to disability. This is recognised by various treaty bodies. For example, General Comment 5 of the Committee on Economic, Social and Cultural Rights (which monitors the operation of ICESCR states that, "since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognised in the Covenant".[48] The Committee goes on to explain that:

> [t]he absence of an explicit, disability-related provision in the Covenant can be attributed to the lack of awareness of the importance of addressing this issue explicitly, rather than only by implication, at the time of the drafting of the Covenant over a quarter of a century ago … [I]t is now very widely accepted that the human rights of persons with disabilities must be protected and promoted through general, as well as specially designed, laws, policies and programmes.[49]

The Human Rights Committee, which supervises the operation of the ICCPR, clarifies that any law adopted by a state which is a party to the Covenant must not be discriminatory.[50] Although disability is not amongst the listed grounds, it is now well understood that disability is included. The World Conference on Human Rights, in 1993, adopted the *Vienna Declaration and Programme of Action* which states that:

> all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities. Every person is born equal and has the same rights to life and welfare, education and work, living independently and active participation in all aspects of society. Any direct discrimination or other negative discriminatory treatment of a disabled person is therefore a violation of his or her rights. The World Conference on Human Rights calls on Governments, where necessary, to adopt or adjust legislation to assure access to these and other rights for disabled persons.[51]

Just as there is international law incorporating the principle of inclusion of people with disabilities, so, too, is there law at domestic level implementing aspects of the principle of inclusion. Domestic anti-discrimination laws, such as the Australian *Disability Discrimination Act* 1992 and the US *Amercians with Disability Act* 1990, give effect to the core ideas of inclusion when they outlaw discrimination and require that "reasonable accommodations" be made.[52] The objective of these laws is to eliminate barriers to inclusion through the rules pertaining to direct and indirect discrimination, and to facilitate inclusion by requiring that steps be taken to make it possible for the person with a disability to participate on equal terms with others.

Accommodations required by anti-discrimination laws have included kerb-cuts (creating a ramp-effect at street crossings to allow wheel chair mobility); braille symbols on Automatic Teller Machines; captioning on films; and adaptations to schools and workplaces. Most laws do not

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[47] See for example the Preamble and Articles 1 & 2 of the *Universal Declaration of Human Rights,* Adopted and proclaimed by *General Assembly resolution 217 A (III) of 10 December 1948*; see also *International Convention on the Rights of Persons with Disabilities*, Article 5.

[48] Committee on Economic, Social and Cultural Rights (1994) *General Comment No. 5: Persons with Disabilities* UNDocE/C.12/1994/13 Para 5.

[49] Ibid Para 6.

[50] Human Rights Committee, (1989) General Comment 18, Non-discrimination HRI\GEN\1\Rev.1 at 26 (1994) Para 12.

[51] World Conference on Human Rights (1993) *Vienna Declaration and Programme of Action* A/CONF.157/24, 25 June 1993 Para 63.

[52] Jones M & Marks LAB "A Bright New Era of Equality, Independence, and Freedom - Casting an Australian Gaze on the ADA" in Francis L & Silvers A (ed) *Americans with Disabilities* Routledge (2000) 371-386

demand complete inclusion of people with disabilities, however. This is because accommodation is generally only required with respect to a limited number of specified areas of life and because any requirement that accommodations be made is always limited by a defense that making the adjustment would impose ‘undue burden’ or ‘unjustifiable hardship’. This means that the cost to the institution, organization or individual engaged in discrimination are balanced against the benefits to people with disabilities. Occasionally the court administering the law will take the big picture, and for example, consider the budget and assets of the school system or business as a whole, rather than focus on the particular shop or on the given school. At other times, the decision-maker’s focus will be on the burden that would be imposed on the individual or the business unit if it were required to make the proposed accommodations.

Law, then, provides for the practical implementation of the right to inclusion. However, the particular application of a law to a specific issue will always be open to debate. So long as all three dimensions of inclusion are present - a non-discriminatory attitude to people with disabilities, access to participation, and facilitation of that participation - the action in question will be legitimate. More often than not, people with disabilities have to work to demand and achieve full and meaningful engagement in every aspect of life. Nonetheless, the existence of human rights law provides a basis for the claim that we are all entitled to equality and to be treated with dignity and respect. It is the principle of inclusion, however, that provides the key to what it means for a disabled person to be treated respectfully and what action is necessary for a person to be an equal member of society.

Conclusion

The principle of inclusion, like all human rights principles, is aspirational and its full implementation requires a transformation of society. Nonetheless, by determining social policy through the lens of inclusion we can begin to shift perception about the difference of disability. As the Vienna Declaration and Programme of Action says, “[t]he place of the disabled is everywhere”.[53] Essentially we are all the same, equal in value and worthy of dignity and respect. However it is not always clear what is required of us if we are to demonstrate our valuing of all people. The right to inclusion provides both the means of deconstructing action and a description of a just society.

Inclusion is the principle at stake when we reject the common-sense view that people with disabilities are primarily disabled by their bodies. It provides a means to respond to the systemic and structural impediments to full participation in society. The inclusion principle comes into play when we demand the fulfilment of the human rights of all people in all aspects of social, cultural, religious, economic and political life. Inclusion clarifies what it is that is being demanded by people with disabilities in a claim for entitlement to human rights.

An inclusive society is a just society. Unless there is an attitude which takes equality seriously and which is committed to non-discrimination, justice will not pertain. Unless there is provision for access of all sorts and in all contexts, people with disabilities will remain outsiders living on the fringes of society. Unless there is facilitation to limit the impact of disability, accommodation that makes inclusion possible and support where it is needed, people with disabilities will be relegated to the margins. Using an inclusion check-list provides a means of articulating the issues and of ensuring all potential sites of exclusion are challenged. Inclusion calls for the right to valued recognition through meaningful engagement. This is what is sought by all people.

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[53] *Vienna Declaration and Programme of Action*, Para 64.