

Should we provide special services for special people?

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Or should we aspire to a world where inclusive services are the norm, and hence 'unremarkable'? Dr Justin Lee, Research Fellow at the Institute of Policy Studies, discusses what it means to be a truly inclusive society.

When meeting or interacting with a young person with disabilities, people often are unsure of how to behave. They may ignore the person or be overly effusive. Can you tell us some dos and don'ts, and some key points to keep in mind.

Yes, the 'overly effusive' reaction is sometimes also called the hero reaction and it usually appears in the form of a compliment like, "I find you so inspiring" or "I am amazed that you can do that" or something similar. These comments, though they show comprehension of the impacts of a disability, also serve to distance the person with a disability from the speaker. However, as disability scholars like Vash and Crewe point out, a disability is always there and living with it is not a heroic act — It is simply one way of living. To make a person with a disability a hero or an inspiration serves to distance the person from "normal" people. While being viewed as a hero may be better than being viewed as a defective wretch, both perceptions marginalise the persons in question and make them into outsiders.

At other times people will ignore the children with disability because they feel embarrassed by the situation of not knowing how to interact with them. One rule of thumb is to keep in mind that they are people first, and they just happen to have a disability, thus the preferred term 'people with disability' rather than 'disabled person'. The disability should not become the master status that defines everything they do. ***Therefore you can treat them on an equal basis with everyone else, but tempered by understanding and empathy of the unique circumstances they face.*** I remember a friend recently telling me that her son was asked to buddy up with a child who has special needs in school. And because he was asked to 'treat him like everybody else', he started to play pranks on him, causing trouble.

These are just general sensibilities, but many voluntary organisations serving people with disabilities will offer guidelines and good practices specific to the disability. There will be too many to list here for that purpose. For example, a visually impaired person will appreciate if you announce your entry and departure, and allowing them to hold your arm if you are leading them rather than pull their hands. Or, making sure that you are face-to-face with a hearing impaired person when talking to them because they may use lip reading to help in understanding. However, sometimes you can simply just ask the person how they would like to be treated.

Parents in their desire to protect such children may end up hindering these kids from reaching their true potential. Your advice to parents who want to empower their kids to lead a full life and participate in society as adults.

I wouldn't pretend to be able to advise parents on what is best for their children, so it may be difficult to determine where the boundary is between taking responsible care of your children and overprotection. However, if you are a parent taking care of a special needs child, there is much more support than just government help and voluntary organisations. Some families engage their whole extended family and larger community to help out in small or big ways, so that the whole experience isn't so lonely and burdensome. A nephew or aunt can babysit. A retired neighbour can help pick them up from childcare. The shopkeepers in the neighbourhood can help keep a lookout.

While many see raising a special needs child as their sole responsibility, and worry about whether they can afford formal care for them, it can be useful to seek informal help from those who may be willing to offer them.

What do we as a society need to know/understand about inclusion for people with disabilities?

In order to create better social inclusion, multiple values, principles and considerations are at play and these should be taken into account. These are some key values and principles that we can use to better evaluate and design inclusive practices.

1. Choice. Is there an existence of an adequate number of viable options that reasonably encompass the diversity of preferences that people with disabilities have?
2. Knowledge. Are People With Disabilities (PWDs) (and their significant others) able to understand the nature and implications of those options as comprehensively as possible?
3. Autonomy. Are PWDs able to autonomously make decisions based on authentic preferences (free from unwarranted influence)?
4. Equity. Are PWDs given a chance like everyone else to access and participate in opportunities?
5. Social Justice. Where PWDs do not have a minimum acceptable quality of life, are they given some advantages to level the playing field in a way that does not overly burden others?
6. Respect. Does society have calibrated and conditional respect for PWDs based on an appreciation of the diversity of abilities?

These values are not a laundry list but form an interconnected whole. There is a sense of priority and sequence. For example, there is no point aspiring to autonomy if there do not exist good options to choose from in the first place. There is also no point in appreciating what the authentic preferences of PWDs are when there is insufficient knowledge about various options to allow PWDs to make rational decisions.

There is also an increasing degree of difficulty as we go down the list. Creating choice is simple in the sense that you can measure what and how many options are available. Measuring equity is much harder, for example, when equal opportunity depends on the discretion of employers, who can claim to have 'given a chance' but assess that PWDs do not measure up to the job requirements and therefore do not hire them. Social justice is even more challenging, as it implicates some kind of affirmative action, and it will be unclear how much

support is considered reasonable accommodation, and how much is considered giving an unfair and unearned advantage to PWDs, resulting in resentment from others.

The list also shares attributes similar to the Maslow hierarchy of needs, where areas that are highest in value, are also paradoxically lowest in priority. We cannot meaningfully aspire to 'higher' values such as respect when 'lower' values such as choice and autonomy are not even satisfied. Because respect is higher in value, it also means it is the most ill-defined. It is also easy to go wrong here. For example, when well-intentioned people give encouragement to those with disabilities, as mentioned earlier.

Please share a couple of examples of successful inclusion policies in Singapore or abroad and some that haven't worked (despite best intentions).

There are some examples of problematic inclusion mentioned in my op-ed on inclusion: inclusive library reading groups in the UK that were perceived to be oppressive (<http://www.straitstimes.com/opinion/ask-the-disabled-how-best-to-include-them>).

It's hard to say authoritatively what is good inclusion...it depends on what dimensions and facets of it (see Values above). For example, the Independent Living movement and Direct Payment scheme privileges autonomy as a value. In direct payments, a person with disability may get a sum of money from the government and can decide what kind of services to buy with that. He or she may then employ an assistant or helper. This is empowering because instead of a 'client' receiving services, they become 'employer'.

Where do you think Singapore would like to be in, say, 5-10 years time in our attitude and treatment of people with disabilities? What changes are we working towards - in schools, the work place and community spaces?

The Enabling Masterplan that the Ministry of Social and Family Development seeks to provide continuum planning and development of comprehensive services for people with disabilities, everything from early intervention to education to employment and community integration. The next EM will start its process again in 2016 next year, whereby policymakers will engage the community to do the next round of master planning. One big question is whether children with special needs should be educated in mainstream settings or not? In special schools, children get a safer environment and specialised attention, but also do not get enough exposure to mainstream settings. In employment, the question is whether the people with disabilities should be encouraged to work in sheltered workshops (typically low wages) or be pushed to open employment as far as possible. These questions are complex and do not have a simple answer. ***A unifying theme seems to be: should we provide special services for special people? Or should we aspire to universal design, where services are already inclusive and everyone can use them?***

In general, universal design is more ideal because it makes inclusion unremarkable.

Many of our services and policies are intentionally designed to be inclusive. There are inclusive playgrounds, inclusive gyms and integrated childcare. These are useful attempts to move one step closer to a more inclusive society. However, they are like the specially designed 'reserved seats' in the public trains that indicate they should be given up to a senior,

pregnant woman or person with disability when there is one present. This is a kind of noticeable inclusion, where accommodations are intentionally designed and clearly communicated to the public.

However, some forms of inclusion are less noticeable. For example, in the spirit of universal design, if regular toilets are already wide enough to accommodate wheelchair users and have grab bars for seniors, it can already accommodate most users. There will be no need for specially designed services. **In that sense, true inclusion is unremarkable.**

But this is not possible for different types of assets or services, e.g. accessible car park. While you can give up your seat to a person with disability on the train, you cannot decide to 'give up' the car park lot to a person with disability because you won't be there to do so. Therefore, there are some areas whereby 'reserved' or 'specialised' services make sense.

The BCA in Singapore has done a lot to advocate for universal design of our built environment. I suppose there is also a lot we can do for our social environment.

What can we as individuals do to further this process of empowerment and inclusion for PWDs?

We are often exhorted to appreciate and value the diversity of people with disabilities. This is easier said than done despite the best intentions. I think it is because we have a natural tendency to rank and evaluate people and make decisions based on that: we want to figure out who is smarter, stronger, better looking, who is a better boss, which employees are performing, what social causes you should donate to etc. And because these decisions can actually become quite complex, we end up taking short-cuts to simplify those decisions. Sometimes we use one set of criteria to measure people, and that allows you an easy but incomplete assessment of a person's worth. And when a person falls short, we think of rectifying that weakness. This has been the approach that the medical model uses in trying to correct for the functional impairments of people with disabilities.

It is also possible to take a 'strengths-based' approach: To see what unique attributes a person has that can be cultivated, even if those attributes are not typically recognised or appreciated by the mainstream. This does not mean going overboard to adopt some kind of extreme and misguided political correctness whereby any and every difference is identified and elevated as valued attributes. Instead, it means being more open towards a wider diversity of differences that may be of value.

One way to overcome our mental barrier — our natural tendency to evaluate people based on standard and mainstream criteria — is to appreciate that we all have some kind of variation in abilities, and some of these variations we regard as 'normal differences' while other differences we regard as 'abnormal differences' that we stigmatise. Being short-sighted is not considered to be a disability and being left-handed is no longer stigmatising even though it was historically. We should exercise more generosity in widening the pool of what is considered 'normal difference' in human diversity. Or, as a respondent once told us in an interview, "People with disabilities are no different in the sense that we are all different"

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