It takes a village to raise a child:
Resisting ableism when we raise our children with disabilities

Katarina Luce and Sarah Brown

In this article we talk about:
- how it can take families a lot of work to build relationships between their disabled children and the people who will be part of their lives – the people in their 'village'
- this is because of how society assumes that 'normal is best' and feel scared or don't know how to connect with people different to themselves
- at the beginning it can be hard for families when people compare children and assume children need 'help' to get 'better' at things like walking or talking
- children with disabilities often get sent to school far away, outside the communities they live in
- this can mean children miss out on chances to build relationships in their area, but it also means the community misses out too because they might not get the chance to know them so well
- often schools focus on targets that mean many people fail
- we want schools to be a place where all people are valued and not only measured on their academic ability
- services for disabled people are often not designed for everyone from the start
- we think families need people to be alongside them, not always 'fix' people
- how Katarina has re-written the story of her son, to connect with him and see him for who he is
- celebrating relationships means we create a village where everyone is included and valued.

So, the proverb goes, *"It takes a village to raise a child"*, and we know that even before a baby is born, the nature of a parent/carer's relationship with their "village" changes and they see the beginning of their child's relationships with their family and their community develop. These are relationships that will keep them safe, nurture them, support them and define them; relationships that we know have the power to enable or disable them.

For new parents or carers, the world can slow down and they have time to meet people and notice who's around. They see the people in their street, in the shop, park, library or school on a daily basis. These people smile, say hello, talk to the child and notice and ask questions; they are invested in those relationships. Yet parents and carers of children with disabilities know that from the beginning, ableism pervades every aspect of their lives, so that the *"emotional labour"* (Runswick-Cole, 2013) required to build the village and to help their children and themselves have a chance of an ordinary life, is extraordinary.

How it begins: Ableism, diagnosis and early intervention

Katarina: My son has complex needs. He has cerebral palsy and is non-verbal.

When he was born he was very ill. The doctors were desperately trying to find out what was 'wrong' with him. They kept coming back to one diagnosis that seemed unlikely but possible. I was told several times, in several different ways, that it would be 'very unlucky' if my son were to have contracted this particular illness. As it turned out, that was exactly what had happened. We eventually left the hospital and I've never quite shaken the feeling that he wasn't seen as the gift we felt him to be. This feeling has continued, although thankfully I have developed a stronger sense of injustice in the face of this alongside a stronger sense of pride and clarity around who my son is and what his offer to the world is. I have had to rewrite the narrative of his offer, which did away with comparisons and measurables, and find my own framework to connect with him and a new lens through which to view him.

From the very beginning, ableism constructs children with disabilities as *"lesser, undesirable, in need of repair or modification and dehumanized"* (Hodge & Runswick-Cole, 2013). Ableism is at work when there are no positive images, words, or looks of joy reflected back to you as new parents; when people lean into the cot with worry or fear on their faces rather than wonder; when there isn't automatically a 'place' for your child in their local school, when you're told *"this isn't the right peer group for your child"*. Ableism excludes children from spaces in their community that they need, like all children do (think inaccessible playgrounds, schools miles away), and it does the same to parents. Milestones are measured and recorded, and flagged if they are considered late. All sorts of language and rituals around the birth starts the caregiver's journey of targets and comparisons. Children are filtered off into 'early intervention' (often taken for granted as a valued project) and separate spaces; which are both *"the result of and relief from ableism"* (Hodge & Runswick-Cole, 2013) and where the ableist task of becoming as 'normal as possible' as quickly as possible begins. It can be a reoccurring shock to realise your child is set apart from those who can achieve in a recognised and accepted way, and rarely are you taught to think critically about whether this is the journey you want for your child, because 'normal' is taken for granted as the best and only way.

Who gets a place in the village?

When people tell me I *"deserve a medal"* whilst casting furtive glances at my son and say *"I couldn't do what you do"*, I appreciate the fact that they think so highly of me, but I actually know that's not the case at all. What they are really doing is rejecting my son and making assumptions about who he is and what he 'offers' the world. Moreover, they are shifting responsibility from themselves by seeing me as somehow 'gifted' with the ability to care well, care better and cope so well. They simply are not needed in the process, robbing both me and my son of the community that is an everyday occurrence for other children and grown-ups.

My son absolutely could not access 'mainstream' education within its current model because ableist notions and practices would make my son invisible and force him into a position of failure.

Oliver (1990) said school is a site for the politics of disablement. Schools are communities, and reflect communities too. Schools are central to our notion of the village, as is their role in a child's life, and their families by extension. Specialist settings have children attend from far and wide rather than serve one geographical community as other schools often do. If my son isn't seen in a mainstream school (and we would argue he can't be through an ableist gaze) what is the implication for him? My other children do attend mainstream and when they have lessons on disability and inclusion the message is clear; people with disabilities are just the same as us; they can do everything you can do if the barriers for them to be involved and included are removed. Caregivers who have internalised ableism often try and minimise the differences of their children to ensure they 'fit in' as much as possible, that they are measured alongside the most acceptable human characteristics and are seen just like everyone else. This comes at a cost to both the children and their families, but furthermore it validates the notion that some people really are just too different to pass as human. Perhaps it seems radical to suggest educational systems where all individuals can be valued because of their very human nature, but wouldn't this shift ensure all people thrive and connections become the essence of how we learn? The feminist poet and activist Audre Lorde said that *"without community there is no liberation, but community must not mean a shedding of our differences, nor the pathetic pretence that these differences do not exist"* (Lorde, 1984, p. 112). Difference makes us human, it is unifying, strengthening and is a cause for celebration.

Ableism in services

Ableism also pervades services for children including the disabled community and specialist services in similar ways to the wider community. It is possible to see a hierarchy of disability that is reflected in people's use of language, perceptions of 'ability' and validity of personhood. 'Accessible' opportunities are often more accessible for those further up the hierarchy, usually those more 'verbal' and mobile. Therapeutic interventions and resources are frequently designed and *then* adapted/ made more accessible. Rarely are all services being designed from the start, with everyone and for everyone. This has a raft of consequences for my son, for his opportunities, for his connections and for his life chances; it leaves him without a village.

Of course what we'd really like is a society where 'specialist services' are not needed, where your family can be connected enough to your village so that they are redundant. In the absence of that, an examination of ableism within services and the benefits of making systemic changes, rather than considering inclusion an issue for individuals, is imperative. An example of radical cultural change in services happened during the covid pandemic; when the world experienced disablement, it used technology to adapt for everyone (for example video conferencing), rather than consider this an individual problem.

Alongside this, services having the space to raise consciousness around ableism and how you can deconstruct the narratives of ability /normality, would make a difference. Most of all, an approach based on being alongside you, not 'fixing' your child, in our experience, can make a big difference; giving space for validation and celebration of children for who they are.

A village for everyone

As well as driving changes within services the pandemic also proved to be a time that people considered their community and forged links which did not exist previously. In some ways the crisis highlighted our common sense of humanity and afforded people a different view of those around them, often for the better. Perhaps another example of how redefinition and togetherness benefits all.

In our village, the one built slowly, carefully and with a great deal of consideration and effort, people know that my son has a soul that is vast and joyous and about as human as a soul can be. His 'offer' to the world is spellbinding and unique with more depth and complexity than I can give words to. This is the kind of village that people are lucky to be a part of. Families who have a child with disabilities should be supported to notice their child in connection with themselves, rather than in comparison to others, which is how services are currently rolled out, including within the realm of school and education. This onus on relationships would ensure special credence is given to valuing your child for who they are, not for who they are not, or who they should be in order to be truly valued and included. In doing so, all children can be celebrated, valued and be seen. We believe this would have a huge impact on how children with disabilities could take their rightful place in their communities – alongside other children. Valuing relationships in this way would benefit all, as difference would become less relevant in the face of strong human connection.

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References
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"Normal" is a setting on a washing machine, not a person

TK Vincent

What is the article about?
A discussion about disability in terms of professional models, intersectionality, and representation. There are also some suggestions for good practice.

What is dis/ability?

Under the UK Equality Act, 2010, a disability is *"…a physical or mental impairment that has a 'substantial' and 'long-term' (12 months or more) negative effect on your ability to do normal daily activities…"* and one of the nine protected characteristics protected by law from discrimination. However, this is not the only definition. For some, a disability is the way they experience life, and they do not perceive their disability as making them less. Rather, they believe society creates barriers and hostile environments for anyone who is not able-bodied (known as ableism). Unfortunately, ableism as a term has not entered the general population's vocabulary in the same way that other terms to describe discrimination have, and this indicates that social change for this group is still in need of enthusiastic championing.

A stark picture:
- People with disabilities make up 15% of the world's population, and 14.1 million of them live in the UK (Scope, 2021a).
- Life costs an extra £583 a month on average if you're disabled but disabled people are almost twice as likely to be unemployed (Scope, 2021a). This tells us we have a long way to go to ensure equal employment opportunities for all sectors of society.
- 8% of children in the UK are disabled, yet *"…new research commissioned by Scope and the Disabled Children's Partnership (DCP) reveals the annual funding gap in disabled children's health and social care has grown to £2.1 billion"* (Scope, 2021b).

The barriers that isolate disabled people from connecting and contributing loom high even now. Have you ever stopped to think about why? Have you considered how you may be contributing to the status quo?

Why do models matter?

As I am a social worker, and a trainee family and systemic psychotherapist, and a disabled person, perhaps I can see some barriers that exist for disabled people more easily than others can. As therapists, social workers, or health professionals, it is worth considering which default lens we see the people who need our support through, how each one will distort what we see, and how that can impact our clients or families.

The medical model can help us consider how a client can be supported physically (be it with aids, or medically) to alleviate or to manage symptoms. A diagnosis can be key to accessing relevant services and support. A diagnosis can help provide explanations that can be transformative in a person's ability to accept differences in their life experiences from others. However, focusing only through this lens can result in tunnel vision – an emphasis on a "cure" where in many cases no such desire exists in the person with the disability, or be problematic where no medical treatment is available. It can also lead to an emphasis on the production of support where the eradication of symptoms is the focus, which doesn't necessarily leave disabled people leading happier or more fulfilling lives.

The social model of disability identifies systemic barriers, derogatory attitudes, and social exclusion, which make it difficult or impossible for individuals with impairments to live life with the same opportunities as others. The model's belief is that people are disabled by barriers in society, rather than their impairment or difference. Through this lens, agents of change can explore a system's barriers

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