**Self-Determination**

**What is Self-Determination?**

The NGSD states that ‘People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving and making decisions about their lives.’ (NGSD, 2011)

More simply, self-determination can be defined as:

*Making things happen in order to maintain or increase your quality of life.*

While the concept of self-determination can be simply defined, the process of being self-determined is much more complex. Many factors can influence and inhibit true self-determination which means that no one is ever fully self-determined, but everyone should have the opportunity to be as self-determined as possible (Wehmeyer, no date).

Academic research has broken the concept down into multiple component skills which people who are self-determined will display (NGSD, 2011; Algozzine et al 2001). These skills include:

* choice and decision making
* problem solving
* goal setting and attainment
* self-advocacy
* self-management
* self-awareness and understanding

Most people will gain these skills naturally throughout their lives, but for people with learning disabilities this is often not the case. Research has shown a positive correlation between IQ and someone’s level of self-determination, but it has also found that IQ is not predictive of someone’s capacity to be self-determined (NGSD, no date). This demonstrates that people with learning disabilities must face more barriers to acquiring the skills which support them to be and demonstrate that they are self-determined.

**Why does self-determination matter and what makes it distinct?**

Multiple studies have shown that being more self-determined predicts a higher quality of life (NGSD, no date), but current UK policy and practice in learning disability focuses instead on other ideas such as independence, control and choice. While this has led to drastic improvements in the lives of many, it could be argued that focusing on supporting people to become more self-determined might have a greater impact going forward.

*Independence*

Complete independence is rare, and most of us live interdependent lives. Many people will always need support to be able to do things. Striving for independence is therefore unrealistic and might create an environment where people feel like they are continually failing.

Self-determination does not require that an individual does something by themselves, but that they cause the thing to happen. For example I could want a cup of tea and ask someone to make it for me. I did not then get a cup of tea independently, but I did cause the cup of tea to be made.

Self-determination therefore acknowledges and allows for people to live interdependently.

*Control*

Similarly, striving for control might be limiting as many people are never or go through periods in their lives where they are not in control for reasons such as mental health issues. People can however be self-determined and continue to make steps towards improving their quality of life even when they are not fully in control.

*Choice*

Choice is key to self-determination, however there are many ways in which 'choice' is currently used in a way that does not develop or demonstrate true self-determination.

Individuals can be offered a choice between 2 options when they actually wanted a third different option. For example you could be offered a tea or a coffee when you really wanted an orange juice. If this happens, the individual is making a choice, but the outcome will not be self-determined as it doesn’t reflect what they actually wanted. In this circumstance the power therefore lies with the individual who is offering the choice.

Equally a choice may not end in a self-determined outcome if an individual does not understand what they are choosing. For example, if you are offered a ‘mocha frappachino’ and not given any additional information about what that is, you might say no when in reality you would like it. Choice therefore needs to be informed in order to be true.

Within the concept of self-determination, choice might sometimes be even more complex as often people make decisions that go against their immediate needs if they believe that will improve their quality of life in the long run. For example you might not want to get out of bed at 6am on a cold morning, but you might choose to in order to go to gain the benefits of going to work.

These examples demonstrate how someone might on the surface seem to have choice in their life, but in order for them to become more self-determined, these choices must be as open and informed as possible.

**What helps people become self-determined?**

Much of the research around self-determination and learning disability has focused on interventions and ways to teach discrete skills such as decision making and problem solving (Algozzine et al 2001). While there are examples of successful interventions for some skills, other more complex components of self-determination are harder to teach. Research also demonstrates that teaching the component parts of self-determination can be both time and resource heavy, with interventions needing to be individualised (Wehmeyer, online).

Targeted interventions are just one aspect of people’s journey towards becoming more self-determined. Barriers created by the environment and stemming from the expectations of others need to be altered to allow individuals to have opportunity to develop and embed skills in real life (Wehmeyer, Kelchner and Richards, 1996). Although there is very little research on how adopting this form of social-ecological model without specific taught input might impact on someone’s self-determination status, understanding and removing environmental barriers to self-determination could create an environment where natural learning would be most likely to occur.

As discussed, being offered choice and exercising choice are very different. Having opportunities to make decisions without excess influence of others is key to becoming more self-determined (discussed further below), but so is access to information. People with learning disabilities often have many fewer opportunities and experiences than the wider population. Simply having a broader variety of experiences allows an individual to get to know themselves more; their likes and dislikes, strengths and limitations. This in turn supports more informed decision making and a greater ability to understand what you can do and where you might need support in order to work towards your goals.

Having more opportunities and experiences will also show people ways in which life could be better. Knowing that there are other possibilities can motivate people to want to improve their quality of life. The more limited opportunities for people with disabilities might cause them to expect less. Creating an environment where people are supported to have the same opportunities in life, work, and relationships will therefore increase everyone’s expectations and motivate people to be more self-determined.

Being self-determined also requires a capacity for self-advocacy and expression. There are many methods that can be adopted to support individuals with more complex communication issues to be able to express themselves, but on top of this an individual needs to know the value and power of their own perspective. If your opinions are constantly being dismissed you may start to believe that they are not important and not worth expressing. By demonstrating to an individual that what they say does matter and that it has an impact, that individual will believe more in their own value and might start expressing themselves more.

Working towards a goal requires an individual to be able to plan, action and evaluate ways of attaining what they want. In life things often get in the way of plans and so problem solving is an important skill to support self-determination. Because there are often multiple ways to solve a problem, it could be argued that all of these skills are best learned through natural situations where an individual is able to try things out and take risks. An environment where this is encouraged and where opportunities are not taken away just because someone makes a mistake will allow for an individual to become more self-determined.

**What gets in the way?**

Some of the ideas that support the natural development of self-determination skills are not that radical or different to ideas that are already directing best practice in learning disability services. We place value on people having opportunities and being listened to. Person centred planning approaches work to support individuals to think about improving their quality of life and plan towards making that happen. However the reality is that many people with learning disabilities still do not have the same life experiences, such as work and relationships, as the rest of the population. So what is getting in the way?

It has been argued that over-protection is one answer to this question (Miller, 2014). Adults with learning disabilities are viewed as a vulnerable group. While it is right that people may need help to reduce possible harm, this label can often act to give licence to protection that prevents individuals learning to deal with normal challenges and difficult experiences that life brings.

Additionally as people with learning disabilities do often need a higher level of support for their day to day lives, this can mean that other people are more intimately involved in decisions that would normally be left to an individual. This immediately makes self-determination harder as your voice will always be competing against others. Research has demonstrated how staff can have considerable power over opportunities for an individual to be self-determined (Brown, 2014) and balancing opportunity and protection when supporting someone is incredibly skilled. For families there may be emotional factors that cause a tendency towards protection. For staff there are issues of duty of care, accountability and input from others such as families. All of these factors lead to a culture which is still risk averse and this is likely to be a factor preventing people from gaining the skills for self-determination.

The way in which individuals are supported could also be a factor which gets in the way of them developing the skills for self-determination. Everybody learns self-determination skills through testing out their capabilities, trying things out and making mistakes. When an individual is being supported, our natural instinct is to try to help someone succeed. This level of support however could get in the way of individuals gaining the skills to be able to do things by themselves. Stepping back and allowing an individual to do things for themselves could be seen as a lazy option and can feel extremely uncomfortable, but might also allow someone the space to find out what they are capable of.

Finally, it has been suggested that low expectations should be viewed as an equally important barrier to the self-determination of individuals with learning disabilities (Wehmeyer, no date). It is still rare for adults with learning disabilities to be working or married or even hanging around in the local bar on a Saturday night. As a result, no matter how much they may wish for this, staff, families and professionals generally do not truly expect these outcomes as being realistic for the individuals they support. They might again then fall back into a risk averse stance and prevent self-determination in an attempt to protect the individual from disappointment.

**What does this mean for practice?**

This research demonstrates the importance of supporting people to continue to move towards being more self-determined. While there are some practices that already work to support this there are other ideas that could be added to our understanding of best practice which would further support people to be self-determined. These could be summarised as:

* Continue to expand opportunities and experiences
* Continue to place value on the individual’s voice, show how it is valued and has power
* Increase our expectation of others and support them to increase their expectations for themselves
* Think about the appropriate level of support
* Promote life-enhancing risk and learning through real life situations

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