Chapter 12

Beyond reasonable adjustment: autistic-friendly spaces and Universal Design

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Introduction

Universal Design (UD) is arguably preferable to design based on 'the mythical norm' or 'the myth of the average' (as described in this chapter), which is supplemented later by 'reasonable adjustments' to assist people who 'do not conform'. Rose et al (2006) emphasise the pragmatic nature of the UD approach to eliminating barriers via initial design, rather than trying to overcome them subsequently through individual adaptation. Principles of UD originated from the field of architecture and environmental design and were taken up within education as Universal Design for Learning (UDL). By planning to meet diverse requirements, UD is an integrative holistic approach that is for everyone's benefit, rather than an inefficient system of multiple individual adjustments fitted retrospectively to try and solve access issues.

UD and the social model of disability are close bedfellows and an historic understanding of the social model will aid understanding of UD. In 1976 in the UK, the Union of the Physically Impaired against Segregation (UPIAS) published Fundamental Principles of Disability, the first text to claim that it was an inaccessible society that caused so many problems for disabled people and not their impairment per se. Oliver's (1990) definition of disability illustrates the social model:

'The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.'

(UPIAS, 1976, p3-4, in Oliver, 1990 p11).

UPIAS was set up by people with physical impairments but removal of the word 'physical' makes Oliver's definition resonate with the wider disability movement. UD is conceived as an approach to removing disabling barriers.

Architecture and education are conceptualised here in the broadest sense, given that learning can take place anywhere at any age, and environment is a fundamental consideration for everyone. Within this chapter, the principles and practices of UD, including UD, will be explored in relation to the needs of autistic people and people with intellectual impairments.

Reasonable adjustment

A reasonable adjustment is an alteration made to enable a disabled person to carry out 'normative responsibilities', such as work (a 'normative' practice being aimed at the 'normal' or 'average' rather than 'atypical' person). This may be an alteration made to enable a disabled, or, shall we say, rather contentiously, 'non-normative' individual to carry out normative responsibilities, such as a job. Instead of making reasonable adjustments for the special requirements of some, UD is based on the premise that environments that are accessible, usable, convenient and pleasurable lead to benefits for all. Arguably this is just good design practice.

The notion of reasonable adjustment raises the question: 'what constitutes reasonable and who decides?'

Introducing the 'mythical norm' and the 'myth of average'

Exercise

- → Try and describe, draw or in some way represent 'the mythical norm' person.
- → What does he (probably he) or she look like? How old is this person? What is their ethnic origin, religion, sexual orientation? Presumably they are not disabled in any way?
- → Think about what was going on in your head while you were carrying out this exercise.
- → Answer the following question yes or no.
- → Is there such a person as the mythical norm? Or shall we call him 'mythical Norm'?

If 'mythical Norm' isn't real, should we be designing for 'Mr Average'? Is HE real?

Exercise

Describe Mr Average and what he needs from society, from education and from life.

We have just invited you to carry out an impossible task. Todd Rose's (2013) TED talk uses 'the myth of average' to explain UD. Rose dated the 'myth of average' idea to the mid-1950s, explaining that, in essence, if researchers take the same 10 body measurements from a large group of people, a mean average size for each measurement can be obtained. However, if they then attempt to work out how many people are of average size across all 10 measurements, the answer will be zero. Humans have jagged physical profiles so for some measurements, individuals will be above the average, for others below, but no one will be average across all dimensions. The problem is that often when products or environments are designed, they are designed to fit the 'average' person, (or as we call him, 'mythical Norm') and 'mythical Norm' does not exist.

Origins and principles of UD

The 'myth of average' was picked up by Ron Mace, an architect, product designer, educator and later director of the Centre for Universal Design at the North Carolina State University (CAST, 2014). He worked on UD for three decades before it was adopted into US federal law in 1990 with the passing of the Americans with Disabilities Act (ADA), which stated that all public spaces must be created using the principles of UD (Meo, 2008). Some parallels can be drawn here with the UK Equality Act (2010), although UK legislation is far less specific about UD.

Rose (2013) extended the idea of the jagged profile beyond physical characteristics to cognitive traits including memory, language skills and attention span, thus bringing UDL principles under the UD umbrella.

Having rejected 'mythical norm/average', let's think about real people in all their rich variety and consider ways in which UD might help to build a society which is designed to cater as effectively as possible for everyone. Our focus is on autism and intellectual impairment and we argue that UD and 'autism friendly' design go hand-in-hand.

Principles of UD

UD as a philosophy is governed by the following seven principles:

- → Equitable use
- → Flexibility in use
- → Simple and intuitive use
- → Perceptible information
- → Tolerance for error
- → Low physical effort
- → Size and space for approach and use

Equitable use

Design should be useful, appealing and marketable to people of diverse abilities. It should provide the same means of use and avoid segregating and stigmatising users.

Flexibility of use

Design should accommodate diverse preferences and abilities, and be adaptable to the user's pace. Autistic people are often associated with rigidity and inflexibility in their way

of being, but arguably this is a criticism which can be levelled at a society and an education system which is not necessarily autism friendly.

Simple and intuitive use

Design should be simple and easily understandable, despite limited experience, knowledge, language skills or concentration levels. Products, buildings, systems and curriculums should seek to minimise unnecessary complexity, by for example arranging information clearly, consistently and in priority order. Clarity is not only important for autistic people and can be of benefit to many.

Perceptible information

Design should communicate all necessary information via varying sensory modalities, with adequate contrast between essential and non-essential content. Autistic people are known to often struggle with sensory overload and UD would take this into account. UDL principles would involve thinking very carefully about the sensory environment in any educational setting.

Tolerance of error

Design should seek to minimise hazards and the adverse consequences of accidental or unintended actions, through providing fail-safe features or by specifically encouraging focused engagement. Autistic people often find ambiguity difficult and relish clarity, which is clearly essential in risky situations.

Low physical effort

Design should be comfortably usable with the minimum amount of fatigue induced, allowing the user to maintain a neutral body position and minimising sustained physical effort. UD is inherently friendly towards an ageing population, for whom physical effort can become more of an issue over time.

Size and space

Design should be of appropriate size and space, allowing for users with varying body size and mobility, e.g. making all components of a design within comfortable reach for a seated or standing user. Again, UD benefits elderly people as well as individuals of all ages with motor and mobility impairments. An inclusive education formulated within an UDL framework would minimise physical access concerns.

All these examples illustrate the benefits of UD for all and are not limited to a specific focus on the requirements of autistic people.

Example

In a self-catering kitchen in a youth hostel there are laminated notices next to the microwave, the oven and the dishwasher, which explain clearly and sequentially, using visual symbols, exactly how all these appliances work. This not only benefits autistic youth hostellers but also helps international travellers who do not speak English. It reduces the requirement for a 'special' solution for the minority who can't read or can't read English, or who just relate more easily to diagrams. Clearly someone was wearing their UD hat and flexing their empathy muscles when they designed this space for diverse users.

What is Universal Design for Learning (UDL)?

UDL is relevant to all learning environments and underpinned by beliefs of equality, inclusion and social justice, and the conviction that all learners, across age ranges, deserve the chance to do as well as they can. It is a way of designing teaching and assessment methods to enable a wide range of students to engage in learning at school or college, in the workplace or anywhere else. UDL was developed in the USA in the early 1990s by a team of clinicians working with disabled children in a hospital in Massachusetts (Myer et al, 2014). In 1984, they set up a research and development organisation called the Centre for Applied Special Technology (CAST) to research ways in which 'special' technology might assist disabled learners. CAST concluded that while technology was important, inflexible curriculum was creating barriers to learning. The UDL framework was born out of this realisation (CAST, 2014).

Edyburn (2010) described UDL as:

'A framework for guiding educational practice that (A) provides flexibility in the ways information is presented, ... and (B) reduces barriers in instruction, provides appropriate accommodations, supports, and challenges, and maintains high achievement expectations for all students.'

(Edyburn, 2010, p34)

Much UDL research was conducted in school settings, but the principles are relevant to post-compulsory education too. UDL principles can also apply to settings where non-accredited informal learning takes place (such as learning, independent living or work-based skills). While there is an evidence base for its efficacy from the university sector (The Cambridge Annual Disability Lecture, 2016), very little UDL research has emerged recently from further education (FE) or the world of work. FE sector colleagues have little opportunity for research nowadays but the influential Tomlinson report (1996) did emanate from FE and set the standard at the time. This small adult education focused research base makes it necessary to adapt principles which have their foundations in school.

Rather than setting out to simplify content, UDL aims to make teaching and assessment accessible and inclusive, by asking teachers to examine their practice for accessibility. Instead of making bolt-on adaptations for the occasional student, UDL is about designing curriculum for diverse requirements (Glass et al, 2013). Inclusive education practice is founded on UDL and only truly started for disabled pupils in the late 1970s. In the post-compulsory sector, the inclusion of disabled students is even more recent (Martin, 2013). Initially integrated education was about placing learners in 'mainstream' environments and expecting them to adapt. Inclusion demands maximising environmental adaptation and minimising retrospective bespoke reasonable adjustments (De Vroey et al, 2015). Mitchell (2014) has discussed several reasons why inclusive educational practices are not firmly embedded, including large class sizes, negative attitudes, constant demands for assessment and limited resources. Academisation is unlikely to make things uniformly better, but the Children and Families

Act (2014) is relevant up to twenty-five years old and founded on a joined-up multi-agency approach to inclusive education underpinned by UDL.

Edyburn (2010) identified the basic principles of UDL as multiple means of:

- 1. Engagement.
- 2. Representation of material.
- 3. Expression of knowledge.

Multiple means of engagement

Multiple means of engagement refers to the use of various teaching methods and materials that will pique and sustain interest (Glass *et al*, 2013). Some students may be motivated by something new and different while others feel safer with familiarity. Collaborating with peers suits some; others prefer to work alone. Formative and ongoing assessment provides information about individual progress and signals necessary adaptations to teaching (Meyer *et al*, 2014).

Vygotsky refers to (1) learning that could be achieved independently, and (2) learning which requires assistance from a 'more expert other'. He called the difference between 1 and 2 'the zone of proximal development' (Costley, 2012; Vygotsky, 1978). Educators need to know what a student can do alone, aim their teaching above this level and provide appropriate scaffolds towards the higher goal (Meyer et al, 2014). The tyranny of low expectations can inhibit learning, particularly in a disorganised environment and especially for those pupils on the spectrum who may not be easy to engage.

Autistic learners typically find unpredictable change difficult, therefore routines, often supported by visual references, can be helpful. In-depth interests can be highly motivating and very individual, but with skill can be incorporated into the curriculum.

Multiple means of representation

Multiple means of representation refers to presenting material in different ways to accommodate varying approaches to learning and to allow choice (Rose, 2014). Vygotsky describes scaffolding which is gradually withdrawn as the student learns (Meyer *et al*, 2014). A scaffold might be something as simple as a visual prompt or set of guidelines for a task (Costley, 2012). Technological advances have opened up many new possibilities in this regard. Presenting visual information about the routines of the day via an iPad, for example, can help an autistic learner to engage and to feel more secure and less stressed.

Multiple means of expression

Multiple means of expression allows for learners to demonstrate their knowledge in various ways. Autistic learners who do not communicate verbally still require access to self-expression and this is a principle enshrined in the SEN code of practice (2015), which emphasises engaging with the views of every learner and applies up to the age of twenty-five for those with complex requirements.

Example

The setting is a FE college. Eight students are working on horticulture projects in the garden with two learning support assistants (LSAs) and a lecturer. After referring to a plan which was devised in the previous session, each student gets on with their agreed task. Two are following a sequential diagram to transplant seeds with one LSA

providing feedback. Two (one of whom is wearing dark glasses) are pruning roses by watching and copying another LSA. Three are working with minimal support to create a paper-based plan. One is planning a menu based on produce in the garden with the lecturer. He is using the vegetables and a chart as prompts. During the last 10 minutes the group discuss together what they have been doing using a range of communication strategies and prompts. Feedback is given by peers and staff and a plan for the next session is drawn up. Learning is taking place. An understanding of the zone of proximal development, the scaffolding required getting from A to B and the requirement for continual assessment is evident in the planning and organisation of the session.

Example

Michael, Paula and Eli live together in a shared house and are supported to be as independent as possible by a rota of staff comprising Henry, Idris and Zac. Once a week, household tasks are shared between residents and staff in a structured way which allows everyone to contribute to the smooth running of the home within a very tangible framework. The group have negotiated rules to which they refer when sharing out tasks, some of which are more popular than others. Rules like 'if you cook you do not wash up' are displayed in the kitchen with visual reminders in cartoon form as well as words. A list of essential activities has been created in three columns. This was based on group agreement about which jobs were most popular, which were least and which were sort of OK. By mutual consent, cleaning the toilet was deemed to be less fun than watering the flowers. Michael, Paula, Eli, Henry, Idris and Zac meet together on a weekly basis and sign up to their tasks. Everyone is allowed to choose an equal number of tasks from column one (favourites), two (OK) and three (less popular). The chart from which they work includes picture and symbol references and words. Jobs left uncovered have to be shared out, by negotiation, once this process is completed. A large chart has been created for this purpose comprising words and symbols. After the process is negotiated, individual timetables are drawn up based on the information generated. Each timetable is produced in a format which is understandable to the individual and different levels of support are built in as appropriate. Michael's chart is made up of photographs and reference objects and a support worker goes through it with him daily. Paula's is recorded on her outlook calendar and she only asks for help when she needs it. Eli does more garden work than everyone else because this plays to his interests, but he does accept that toilet cleaning duty is on his plan and generally completes the task with good grace and ticks it off his list.

This is an example of an overall system operating at various levels in order to be inclusive of everyone and create a sense of mutual co-operation and community. It is subject to continuous review and evaluation and allows for every participant to contribute in their own way and to develop their own interests and skills.

Autism and intellectual impairmentfocused examples of UD

Visual timetables to make routines predictable not only help autistic pupils, but can also benefit those with other neurodivergent profiles or for whom English is a second language. In-depth interests are also highly motivating and making use of these can aid learning. Autism-friendly screenings in cinemas take into account the sensory environment and may be helpful to anyone who feels overwhelmed by too much chaos.

Ensuring that the REAL principles of Reliability, Empathy, Anticipation and Logic underpin systems helps things to run smoothly for everyone. People who do not communicate clearly and logically, do what they say they are going to do reliably or fail to think ahead empathically in order to anticipate and circumvent potential difficulties do tend to create problems (Martin, 2008). The National Autistic Society describes the SPELL approach which, in keeping with REAL, gives a clear steer on the personal attributes needed to work effectively with autistic people:

'Effective supporters will be endowed with the personal attributes of calmness, predictability and good humour, empathy and an analytical disposition.'

(The National Autistic Society, 2016)

SPELL principles encapsulate UD. SPELL stands for Structure, Positive (approaches and expectations), Empathy, Low Arousal and Links. Structure, including knowing what is going to happen next, makes the world more predictable and makes it easier for an autistic person to navigate the social environment. An atmosphere based on positive expectations building on natural strengths, interests and abilities and underpinned by careful ongoing empathic assessment from a wide range of perspectives is congruent with the SPELL approach. Calm and order are essential components of an anxiety-reducing situation and attention should be paid to the potential for sensory overload. Noise, busy colourful displays, bright lights, strong smells and general clutter can be distracting and aversive. The SPELL framework is complementary to other approaches, including REAL and TEACCH (Treatment and Education of Autistic and related Communication handicapped Children).

A TEACCH classroom would include visual approaches to aid the understanding of routines as well as areas for quiet focus, rather than having every wall covered in bright displays. The Picture Exchange Communication System (PECS) can also be usefully incorporated into a TEACCH classroom.

Conclusion

Providing autism-specific examples of UD goes a little bit against the grain, since UD is about design which is inclusive

of everyone, and UDL is about all learners belonging. Understanding characteristics typical of people on the spectrum, while respecting that every single individual is unique, provides a starting point for thinking about including autistic people when developing UD.

There is an obvious need for autistic input in design practice in its broadest sense, including design of buildings, products, systems, curriculum, policy, and the world and everything in it.

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Additional resources

Children and Families Act 2014:

http://www.councilfordisabledchildren.org.uk/resources/summary-of-the-children-and-families-act

Equality Act 2010:

https://www.gov.uk/guidance/equality-act-2010-guidance

PECS:

www.pecs-unitedkingdom.com/

SPELL:

www.integratedtreatmentservices.co.uk/our-approaches/.../spell-framework

TEACCH: https://www.teacch.com/