

## THEME 3

# PERSONALISATION AND INCLUSION

## HOW CAN THOSE WITH LEADERSHIP POSITIONS THINK ABOUT PERSONALISATION AND BRING IT TO THE CENTRE OF THEIR WORK?

*The change needed to move from a system which does **to** people to a system that does **with** is fundamentally about culture. It is about the way society (including public sector leaders) thinks about and behaves towards people with impairments and those who are perceived as different. While there are pockets where personalisation enables individuals to lead ordinary, self-determined lives, for many people this has yet to become a reality.*

### INTRODUCTION

Despite national government commitments to the inclusion of disabled children in local mainstream schools<sup>1</sup>, very little has changed since the introduction of legislation promoting inclusion in the 1970s and 1980s.<sup>2</sup> In 2021 more children than ever are placed in special schools, many children are out of school due to the lack of a “suitable” place, many families are opting for home education because their children have been failed in both mainstream and special schools and the number of children with SEND being excluded is at an all-time high.<sup>3</sup>

If education, health and care services are to become genuinely personalised and enable children and young people with SEND to lead to inclusive lives, we need to do more to explore and truly understand the deeply embedded values and attitudes about disability.

The introduction of personalisation into public policy in the 2000s was a golden opportunity to think differently about how as a society we think and act around disability. New legislation provided the necessary legal framework and mechanisms for personalisation to work. Together, the Care Act (2014) and Children and Families Act (2014) provide the opportunity to develop a joined up personalised system across children and adult education, health and care:

- **In adult social care services, endless professional assessments were no longer required to determine whether somebody was entitled to or eligible for support from the state, making it possible simply to ask people what support they needed to lead a full and fulfilled ordinary life. Some local areas replaced IQ testing with self-assessment while the introduction of indicative budgets<sup>4</sup> enabled person-centred planning to help people identify for themselves the support they needed and how it would work.**
- **The Children and Families Act introduced the option of personal budgets for education alongside those already available from social care. Personal health budgets followed that enabled people with high health needs to determine their own support.**
- **The option to integrate personal budgets for education, health and care offered the potential to streamline previously lengthy and convoluted processes across a range of agencies each with its own protocols and criteria.**

1. Section 1.26 of the SEND Code of Practice 2015

2. 1976 and 1981 Education Acts

3. Exclusion stats

4. [http://s557941885.websitehome.co.uk/wp-content/uploads/2017/06/03-Fact-Sheet.pub\\_.pdf](http://s557941885.websitehome.co.uk/wp-content/uploads/2017/06/03-Fact-Sheet.pub_.pdf)

However, while personalisation could and should have been a major driver for inclusion, too little thought has gone into what we need to stop doing if it is to become a reality.

*The current system for identifying, assessing and providing support for children and young people identified as having “special Educational Needs” continues to focus on conversations about diagnosis, labels and placements “appropriate” to meet “needs” rather than on how can we make sure that schools are schools for all.*

## WHAT IS PERSONALISATION?

**“The objective of self-direction (and a key objective of citizenship) is to diminish the number of decisions that impact your life that are made by people who don’t know you.”**

*Simon Duffy at the Self-Direction & Citizenship Retreat, Wisconsin, October, 2018.*

In stark contrast to a “one size fits all” approach to service provision, personalisation is about individuals determining for themselves the support they need to lead a full and fulfilling life.

The Cambridge Dictionary defines personalisation as “*The process of making something suitable for the needs of a particular person.*” For disabled people campaigning for equal rights, personalisation means exactly that.

It is possible that, over time, the terminology of “personalisation” may have lost some of its potency as a force for change. Nevertheless, it remains fundamentally important as a construct that recognises children, young people and adults as unique, each with their own aspirations, preferences, skills and needs **and** with the same right to have choice and control of their lives as anyone else.

## DIRECT PAYMENTS AND PERSONAL BUDGETS

*Personal budgets for everybody receiving social care support introduced a more flexible approach, giving people the opportunity to determine their own support even if they did not want to manage a direct payment.<sup>5</sup>*

## ADULT SOCIAL CARE

Disabled people have campaigned for decades to achieve equality and a more personalised approach to support from the state. The Independent Living Fund (established in 1988) and Community Care Act (1996) helped to establish the principle that disabled people should be able to decide for themselves the support they need. The Community Care Act, in particular introduced *Direct Payments* within adult social care – a key development that enabled individuals to use funding traditionally allocated to services to pay directly for the support they needed.<sup>6</sup>

Data for 2019-20<sup>7</sup> suggests that, in England, direct payments made up 23% of the total spend on long-term care “at home”<sup>8</sup> for adults, most of whom have a learning disability or need long-term physical support. Despite this, a recent report from TLAP<sup>9</sup> suggests that, for many people, personalisation is still not working as it was originally conceived:

*It became clear that there is a gap between how direct payments are intended to support a “good life” and the reality of a system that may have become unduly caught up in process.*

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5. A personal budget can also be managed by a care provider through an individual service fund, by a trust or by a council itself. The key issue is that the person self-determines the support they need and this is written into a care and support plan and delivered as agreed

6. Until the Valuing People Strategy (2001) focused on people with learning disabilities and promoted personalisation and personal budgets. Most direct payments were taken by people with physical and sensory impairments

7. The Adult Social Care Market in England (National Audit Office, March 2021)

8. Includes home care, supported living, supported accommodation, direct payments and other long-term community care

9. <https://www.thinklocalactpersonal.org.uk/Latest/Direct-Payments-working-or-not-working/>

## CHILDREN AND YOUNG PEOPLE WITH SEND

Personal budgets and direct payments have been available to the parents of disabled children (as well as 16/17-year-olds) since 2001. From April 2014, personal health budgets/direct payments became available for some health services and from September 2014 for some education services.

While there are examples where families and children benefit from personal budgets, e.g. short breaks, home to school travel, children with continuing health care needs, the position remains far short of the original vision of a truly personalised approach to support for children. In January 2021, for example, data that is to hand suggests that just 5.2% of EHC plans (22,000 out of 431,000) included a personal budget. Of these, 18,000 were for social care, 1,630 education and 480 health. Just 606 EHC plans (0.1%) provided personal budgets that integrated funding across social care, education and health.<sup>10</sup>

## WHAT ARE THE MOST COMMON OBSTACLES AND THREATS FACING ORGANISATIONS AND LOCAL GOVERNMENTS IN ATTEMPTING PERSONALISATION?

### Fundamental attitudes and beliefs about children and young people with SEND

In an earlier theme (The Politics of Equity), we used the image of an iceberg, taken from Theory U<sup>11</sup>, to illustrate how fundamental attitudes and beliefs – the “source”, inform the opinions - thoughts - that in turn, shape and sustain the processes, procedures and structures that have developed over time. In this instance, we suggest that a major obstacle to achieving a national support system based on personalisation and inclusion is that as a society, we have still to throw off the legacy of the Eugenics movement<sup>12</sup> that was based on the belief that those who were inferior should not be allowed in society but segregated in institutions or worse.<sup>13</sup>

All sorts of labels emerged to describe those thought to be unfit to be in society - *imbecile, cripple, idiot, defective, feeble-minded, mentally handicapped, educationally sub-normal, in-educable and maladjusted* – many of which crossed over into more common parlance as particularly disparaging insults.

The 1981 Warnock inquiry into special education<sup>14</sup> proposed the generic term “Special Educational Needs<sup>15</sup>” as a less pejorative alternative to labels that were in common use at the time, e.g.: *handicapped, educationally sub-normal and maladjusted*. However, we need to ask ourselves whether simply changing the labels made any impact on attitudes towards SEND. To the contrary, we would argue that labelling is just as corrosive today in that most local authorities continue to plan future provision and services around largely manufactured categories of need (labels) rather a truly inclusive system supported by personalised funding or self-directed support.

### An education system and wider society that are not designed to be inclusive

Children, young people and adults continue to be expected to fit into an education system and a wider society that are not designed with them in mind. While the number of children placed in special schools did decrease following the Warnock report, numbers have risen steadily since 2005, and dramatically so following the introduction of the Children and Families Act in 2014. Indeed, although the large-scale drift of pupils with EHC plans in England from mainstream to special school has slowed over the last 2 years (arguably as a result of existing special school provision becoming significantly over-subscribed) the percentage of children placed in special schools has risen to 1977 levels – before even the 1981 Education Act.<sup>16</sup>

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10. Some caution is needed in interpreting this data due to variations in how local areas interpret and record personal budgets
  11. Presencing Institute – see for example *Leading from the Emerging Future: from Ego-system to Eco-system Economics* (Otto Scharmer and Katrin Kaufer, 2013 *Ego\_to\_Eco\_Intro.pdf* ([presencing.org](http://presencing.org)))
  12. At its height in the mid-19th and early 20th centuries, the Eugenics movement was characterised by a set of beliefs and practices designed to improve the genetic quality of the human “race” by excluding people and groups judged to be inferior or promoting those judged to be superior
  13. In 1913, the same year that saw the introduction of the Mental Deficiency Act that introduced the official categories of *idiot, feeble-minded and imbecile* and established the institutions which later became known as the long-stay mental handicap hospitals housing around 100,000 at their peak, Home Secretary Winston Churchill stated that “*The unnatural and increasingly rapid growth of the feebleminded classes, coupled with a steady restriction among all the thrifty, energetic and superior stocks constitutes a race danger. I feel that the source from which the stream of madness is fed should be cut off and sealed up before another year has passed.*”
  14. <http://www.educationengland.org.uk/documents/warnock/warnock1978.html>
  15. The Government introduced sub-categories within this term to be able to count the number of children and young people assigned not only the general term but also to sub-categories including moderate, severe, and profound learning difficulties
  16. See, e.g. January 2021 School Census data for England

### **Failure to fulfil the transformational potential of the 2011 Green Paper, *Support and Aspiration***

For personalisation to work, a whole system change is required. This is what the authors of the Green Paper ***Support and Aspiration***, published in 2011, envisaged in acknowledging that the system for supporting disabled children was not working and outcomes were simply not good enough, particularly in terms of living ordinary lives.

There is much that is new and visionary in the Children and Families Act and Care Act that followed. However, in what can only be seen as a missed opportunity to be truly transformative, it is underpinned by a basic framework that continues to focus more on labelling children than instilling a fundamentally person-centred approach. What is essentially legislation that enables personalisation but a governance structure that discourages it.

It has become clear that the legislation is not working and rather than improving the experiences of children, young people and their families it is doing the opposite. We now have evidence from the Parliamentary Education Select Committee (October 2019), the Parliamentary Committee of Public Accounts (April 2020), the Local Government and Social Care Ombudsman (October 2019) and Ofsted/CQC SEND area inspection outcome letters that clearly point to a system that is in crisis. In response, the Government has established a review which is expected to be published in 2022.

### **Continued adherence to the medical model**

The system is struggling to move away from the medical model of disability and to embrace an approach based on a social model of SEND. Disability is still seen as something within a person rather than created by society by exclusive design and arrangements. Schools (and most other universal services) have been organised and run without taking account of the needs of a significant proportion of the population. This is because we have traditionally expected certain groups not to belong and to be dealt with separately. So, when a young person with certain labels uses their legal right to go to their local mainstream school there are obstacles and a process through which no other child or young person must go with the school being able to state that it is unable to “meet need” irrespective of the Equality Act and the legal right to go to a mainstream school. Even when children and young people with differences go to mainstream schools, they often feel that they must fit into an environment that does not support them. *Many children report being bullied, not having friends and inadequate adjustments to ensure that they can access the curriculum. Increasingly, there are reports of children being taught separately from the rest of their peers, in groups with other children with labels. Much of this practice is unlawful.*

## **WHY HAVE SOME LEADERS CHOSEN PERSONALISATION OVER OTHER SERVICE MODELS?**

### **It's the right thing to do!**

*Self-Determination takes the position that the purpose (of public funding) must be related to a person with a disability having a purposeful life, having the ability to seek the same goals that all others have related to personal relationships, membership in the community, and establishing an economic and spiritual future.<sup>17</sup>*

At its heart a commitment to personalisation derives from a fundamental view of social justice, human rights and the importance of citizenship.

### **It works!**

Where personalisation has taken root, there is strong evidence to suggest that it helps to deliver a range of improved outcomes in terms of the lived experience of people with disabilities, stronger and more cohesive communities and better use of public funds.

*Evaluations of self-direction<sup>18</sup> have generally shown that (compared to preceding models) it results in:*

- **higher consumer satisfaction**
- **higher worker satisfaction and job retention**
- **stronger interpersonal connections**
- **more community integration**

17. Nerney T (2004) *Lost Lives: Why We Need A New Approach To Quality*. [online] Available at: <http://www.self-determination.com/index.php/resources/papers-presentations/item/64-lost-lives-the-paucity-of-quality-in-human-services>

18. Alakeson V (2010) *International Developments in Self-Directed Care*. ISSUES IN INTERNATIONAL HEALTH POLICY, Vol. 78: pp. 1

- ***fewer out-of-home placements***
- ***improved physical and mental health***
- ***consumers using a greater diversity of goods and services***
- ***improved access to home and community-based services***
- ***good stewardship of public funding***
- ***very few cases of fraud or abuse***

## **WHAT WORKS TO MAKE PERSONALISATION A REALITY?**

To make personalisation work, leaders in education, health and social care across children and adult services need to be courageous. Personalisation needs a very different mind-set and a complete change of culture. Ultimately it requires the belief that everyone is of equal value and should be able to live the life they choose within the economic and environmental constraints that impact on everyone. It then needs the mechanisms for change to be put in place:

- **A shared vision for change across the local area**
- **An action plan**
- **A programme of training and development for everyone involved in supporting children, young people and adults who need state support**
- **Person-centred conversations to replace a medical model approach to assessment**
- **Changed processes to match a different way of working**

Developing this strategy takes a lot of work on the part of people who are under an enormous amount of pressure to deliver the day to day of dealing with overspending budgets, reduced capacity and a system that is struggling.

Despite this, there are people benefiting from personalisation and living self-determined lives. Where change has happened it has been down to local leaders working with families and people themselves to work out what it would take to enable people to live the life they want to with the support they need. The task we face is to take the learning from where personalisation and inclusion has changed people's lives and make it work for everyone.