The Kilbrandon Report and Disabled Children: Some reflections 50 years on

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Abstract

Fifty years after the publication of the Kilbrandon Report, which paved the way for the creation of the Children's Hearings System in Scotland, this reflective paper revisits what the report had to say about disabled children and young people. It also reflects on subsequent progress in how society perceives and values disabled children. Kilbrandon was well ahead of his time in applying the same principles to all children since, at that time, disabled children were generally seen and treated as different. They are no longer condemned to grow up in long-stay hospitals, receiving five minutes of 'mothering' in any ten-hour period (Oswin, 1978). Since 1964, considerable progress has been made in conceptual understandings of disability in research seeking disabled children's own views and experiences, and in according them the same legislative rights as other young people. Many positive developments have taken place at policy level but significant challenges remain in translating these into practice, for example, in relation to poverty reduction, achieving full inclusion and ensuring a smooth transition to adulthood.

Keywords

Kilbrandon Report, disability, children, reflections

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Introduction

The Kilbrandon Report, of 1964 (Scottish Office, 1995) was concerned with 'children in trouble'; that included disabled children because 'those in need of care and protection' were among the Kilbrandon Committee's concerns. The report made various references to and recommendations about disabled children, albeit within the wider context of 'juvenile delinquency'. Lord Kilbrandon recognised that children and young people's offending was sometimes 'a manifestation of maladjustment or emotional disturbance, often associated with impaired intelligence' (paragraph 176). He was well ahead of his time in applying to *all* children the key principles and values underlying his proposals, since those who were disabled were generally perceived differently, and treated separately, from others at that time. For example, the Committee of Enquiry into the Care of Children, widely seen as a

landmark in the humane treatment of children in care, visited a number of institutions accommodating disabled children and found them to be of very varying standards; in its conclusions, however, the Committee stated 'the mentally or physically handicapped child presents different problems... most of which are outside our terms of reference' (1946, p.175).

In 1964, the predominant view of disabled children in the UK rested on an individual, sometimes called medical, model of disability, with children classified according to IQ level and/or medical diagnosis. Some were at special day schools, others - with more severe impairments - attended occupational centres, while those deemed ineducable were cared for by health authorities, sometimes in long-stay hospitals. Those who had broken the law or were judged unruly could find themselves sent to approved boarding schools.

The aim of this short paper is to briefly revisit the Kilbrandon Report in relation to disabled children and reflect on the progress made since then in how we perceive, treat and value disabled children.

The Kilbrandon Report and disabled children

The report emphasised the need for early assessment and careful diagnosis of problems before decisions about residential placements were taken. It stated that it was not usually appropriate for children with learning disabilities - and various other impairments - to be sent to approved schools and recommended that special education facilities be extended (all in paragraph 181). The committee highlighted the difficulty of ascertaining accurate numbers of disabled children across Scotland (paragraph 174) and a serious gap in services for children who had both learning disabilities and emotional / psychological difficulties (paragraph 176). Noting that certain children presented 'serious problems' within children's homes and should be accommodated elsewhere, Kilbrandon also argued that some homes should develop specialist expertise so they could meet these young people's needs *in situ* (paragraph 187).

Some of the terminology used in the report is dated now (children 'suffering from mental handicap' or 'maladjustment'), nor would we accept today that any young person is 'completely unresponsive to education and training'. However, the inspiration and innovation of Kilbrandon, so far as disabled children are concerned, was the assumption that the same basic principles should apply to their care and treatment as to any other child, a view based on an 'increased awareness and concern about their needs', particularly in relation to those with learning disabilities and/or mental health difficulties (paragraph 245). These principles were:

- an educative and preventive ethos

- early identification and diagnoses of problems

- primacy of the child's welfare

- close involvement of the child's family in discussions about how to meet need

- Community/collectivist solutions to issues relating to 'children in trouble'.

Progress 50 years on

What progress has been made for disabled children fifty years on? That's a question which could be tackled from many more angles and in greater depth than this short paper will allow. The following sections consider conceptual understandings of disability, what we know about disabled children's views and experiences, principles underlying professional practice, and progress and challenges within aspects of policy and practice affecting children's day-to-day lives.

Conceptual understandings of disability and their impact on children's lives

The ethos of normalisation, which emerged in Denmark and Sweden in the late 1950s and '60s, promoted the idea of an 'ordinary life' and a disabled person's right to enjoy a similar lifestyle to other citizens. For disabled children living in institutions, this was an acknowledgment that they shared the same needs and feelings as any other children and had a right to similar experiences in terms of living in a family or homely environment and enjoying meaningful relationships with significant others. In 1970, The Education (Handicapped Children) Act gave all children in the UK the right to attend school. Parents of new born disabled babies were no longer advised to leave them behind in long-stay hospitals and a range of family support services was set up. One of the most significant, in terms of enabling parents to bring up their children at home, was 'respite care' (although note this term implies relief from a burden), initially provided in hospitals and still provided in residential schools and dedicated units. The first family-based short break scheme for disabled children in Britain began in Somerset in 1976 with the first Scottish scheme appearing in Lothian three years later.

From the 1980s onward, the social model of disability, developed by disabled academics and activists (Oliver, 1990), became increasingly influential. It distinguishes between 'impairment' – meaning a physical, sensory or cognitive limitation – and 'disability', referring to the social, material and cultural barriers which exclude adults and children with impairments from mainstream life. Disability is a social construction; if society were arranged differently, people with impairments would no longer be limited in their activities nor face discrimination. The social model has had a far-reaching positive impact on the lives of disabled children in terms of tackling material barriers and promoting physical access. It was the basis for legislative advances such as the Disability Discrimination Acts 1995 and 2005 and the Equality Act 2010.

Nevertheless, the social model has been criticised, *inter alia*, for its neglect of personal experience and the implications of living with impairment. In response, Carol Thomas (1999, 2007) developed two new concepts as part of a 'social relational understanding' of disability. 'Impairment effects' denotes restrictions of activity associated with particular impairments, such as discomfort, fatigue or the inability to do certain things. 'Psycho-emotional disablism' refers to hurtful, hostile or inappropriate behaviour directed at a disabled child or adult which has a negative effect on their sense of self. Psycho-emotional disablism occurs at both a one-to-one level, for example when a disabled child is bullied

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by a classmate, and institutional level, such as excluding disabled children from school trips. Thomas argues that the cumulative impact of psycho-emotional disablism can result in 'barriers to being', affecting what people with impairments feel they can be or become. Research with disabled children has borne out the relevance of this model to their own accounts of their lives (Kelly, 2005; Connors and Stalker, 2007; Wickenden, 2010).

Understanding disabled children's lives from their point of view

Until the late 1990s, most research about disabled children had relied on parents' and professionals' perspectives, usually painting a negative or even pathologising picture of bringing up a disabled child and the impact on family life. Since then, researchers have increasingly canvassed disabled children's views, using a variety of communication methods to suit individual need. Such research has often positioned disabled children rather narrowly as 'service users' but when perceived more holistically - as children - it is clear that their views, priorities and aspirations are much the same as other children's and that many have a positive and/or pragmatic 'take' on life.

A number of recurring themes have arisen in research seeking disabled children's views over the last 15 years or so, including:

- The importance of families, especially mothers, in providing love, support, company and advocacy

- A sense of enjoyment and achievement linked to hobbies and pastimes, playing games, having fun, keeping pets, going on holiday, sports and (even) school work

- The significance of friendship but also, often, a feeling of being left out and a desire for 'real' friends

- The value placed on social activities, formal and informal but also, often, a paucity of available and accessible social and sports opportunities

- Experiences of harassment and bullying, perpetrated by adults and children, in a variety of public spaces.

Children tend to have less to say about the services they use, apart from attending school, parents often acting as an 'interface' with social care and health services and professionals. Parents have consistently reported an ongoing 'struggle' or 'battle' to secure adequate support for their children, but exploring that topic would require another paper.

Principles underlying work with disabled children today

As Kilbrandon proposed, the principles underlying work with disabled children should be the same as for any child, set out in statute and policy. Under the UN Convention on the Rights of the Child (1989), all children have the right to have their views taken into

account in decisions affecting them, while Article 23 gives disabled children 'the right to live a full and decent life in conditions that promote dignity, independence and an active role in the community'. The UN Convention on the Rights of Persons with Disabilities (2006) confirms that disabled children have the same rights and freedoms as others, including the right to express their views about any matter affecting them, receive appropriate support to do so and have their views given due weight, their best interests being a 'primary consideration'.

The Children (Scotland) Act 1995 set out key principles which should inform work with all children, some of which echo Kilbrandon's ethos 40 years earlier:

- Promotion of the child's welfare

- Normalisation /inclusion

- Participation of the child

- Partnership with parents

- Interagency collaboration, and

- Cultural sensitivity.

More recently, a national review of services to disabled children, while reiterating these principles, also included empowerment, choice, control, and striking the right balance between providing protection and encouraging independence (Scottish Government, 2012). Ironically, however, disabled children and young people played little part in the review process.

Policy and Practice

How far are the principles outlined above translated into policy and practice? This section reflects on progress and challenges within some key areas affecting disabled children's everyday lives.

Issues raised by Kilbrandon

It is striking that the Kilbrandon Report identified two problematic issues which are still 'live' in Scotland today: the difficulty of ascertaining the number of disabled children nationally (Scottish Government, 2012) and a lack of appropriate specialist services for children who have learning disabilities and mental health needs (Minnis et al, 2006). The report's other concern about disabled children focused on residential placements. While the number in residential settings is much lower now than in 1964, disabled children remain disproportionally represented among this population. Relatively little research has been undertaken on this topic in the UK, especially in Scotland; however, several studies were conducted at the start of this century. Abbott, Morris and Ward (2001) found that the two main reasons for disabled children attending residential schools were authorities' inability to meet their educational needs locally and pressure on families. Some parents

were extremely reluctant to let their child go to residential school; others may have found it a more acceptable option than adoption or foster care. We know very little about the lived experiences of disabled children in residential settings. However, Hawthorn (2005) warned that they are commonly ascribed the role of passive recipients of care, with staff not always making enough effort to elicit their views and preferences.

Poverty and disadvantage

Disabled children are significantly more likely than others to grow up in poverty: the median equivalised income for households with a disabled child is about 13 % lower than those with non-disabled children (Shahtahmasebi, Emerson, Berridge and Lancaster, 2011). Read, Blackburn and Spencer (2012, p.228) have argued that 'bringing about change for those children and families where child (and in some cases adult) disability intersects with protracted household poverty is arguably the most important and difficult issue for social policy'. Today families with disabled children are entitled to welfare benefits unavailable in 1964 (Attendance Allowance was first introduced in 1971). However, current welfare 'reform', accompanied by cutbacks in public services and media exposés of benefit 'scroungers,' are exacerbating family stress and also stigma (Briant, Watson and Philo, 2013; Stalker et al., 2013).

Services and support

The Children (Scotland) Act 1995 was significant in bringing disabled children into mainstream childcare legislation for the first time. In addition, the Act classified those with impairments as 'children in need' and required services to be designed to minimise the effects on them of their 'disabilities'. This was certainly progress. More recently, self-directed support, designed to extend choice, control and flexibility for service users, has become available to parents of disabled children and to young people aged 16 and over. At the time of writing, it is too soon to say what impact this will have on children's lives. However, due to the way it has been introduced in some local authorities, some parents perceive self-directed support primarily as a money-saving device for public bodies (Stalker et al., 2013).

Another area of practice with disabled children requiring much closer attention and priority is child protection. Disabled children are 3-4 times more likely to experience abuse than non-disabled children (Jones et al, 2012), yet they remain a 'hidden' group within child protection services in Scotland (Taylor, Stalker, Fry & Stewart, 2014) and indeed elsewhere. Here again, disabled children seem to be perceived and treated differently from others, professionals voicing opinions that sexual abuse of disabled children is uncommon or that extensive use of services protects them from maltreatment. Child protection practitioners often feel anxious about working with disabled children, reporting that they lack the necessary expertise and communication skills.

Communication and voice

Linked to the theme of communication, far greater attention is paid to consulting disabled children today than 50 years ago. There are examples of innovative initiatives around Scotland in terms of seeking - and disseminating – disabled children's views, and guidance

on how best to do so is available. Nevertheless, there is still some way to go before all disabled children are routinely included in discussions and decisions concerning them, even allowing for the fact that the method and extent of this will vary with ability and impairment. There are recent reports of social work assessments, for example, stating that a child's view could not be ascertained because they were non-verbal (Taylor et al., 2013).

Generic or specialist provision?

Despite all the talk of inclusion, there remains a continuing tension between generic and specialist provision for disabled children, not just in Scotland but UK-wide. A telling example lies in the UK Government's ratification of the UN Convention on the Rights of Persons with Disabilities (2006) but its self-exemption from Article 24 which stipulates a commitment to ensure an inclusive education system. So long as mainstream services do not provide adequate support for disabled children, parents and professionals may understandably opt for segregated placements. However, the longer these are maintained, the less effort and resource will go towards opening up mainstream provision.

Transition to adulthood

This section cannot finish without reference to the vexed issue of transition to adult services - a notoriously difficult time. A raft of policy initiatives surrounds transition but their complexity and lack of 'joined-upness' has, it seems, driven many families to despair. Schools carry the main responsibility for forward planning as disabled pupils approach adulthood but they do not always have good knowledge about the range of potential options young people can move on to, particularly, again, those which support social inclusion. Research a decade ago found that arrangements for young disabled people leaving residential care were often made at the last minute, the young person having limited opportunity to exercise choice (Priestly, Rabiee & Harris, 2003). These issues are being tackled by the Scottish Transitions Forum, a multi-disciplinary, cross-sector body which promotes good practice, provides learning resources and challenges a deficit approach to transition. (See http://scottishtransitions.org.uk/about-the-scottish-transitions-forum/).

Conclusions

Considerable progress has been made since 1964 in the way society views, treats and values disabled children. No longer are they brought up in hospital receiving, as Oswin (1978) chronicled, five minutes of mothering in any ten-hour period, denied an education or excluded from mainstream childcare policy and legislation. Conceptual insights from normalisation, the social model of disability and the social relational understanding have contributed to a more nuanced appreciation of the complexity of disability and how disablism can affect children's lives. Over the decades, the predominant ethos affecting the way we treat disabled children has shifted from othering and exclusion, to care and protection and, now, justice and rights. Disabled children themselves have spoken about their likes, dislikes and aspirations. All these developments have informed progress at

policy level, with young disabled people now accorded the same rights as others within international convention, national legislation and local initiatives.

Progress often falls short, however, when it comes to translating good principles and policy into action, particularly in providing the support required to put disabled children on a level playing field with others, economically, socially and in terms of citizenship. There still appears to be a lingering view that disabled children are different from others in some undefined but negative way, while inclusion can be interpreted narrowly, minimising impairment effects and failing to make appropriate adjustments.

There is no clear means of monitoring local authorities' practice in this regard and a 'postcode lottery' persists. A positive way forward would be for Social Care and Social Work Improvement Scotland to carry out an inspection of the quality of services for disabled children, young people and their families, which could then form the basis for Scottish Government guidance.

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