





Autonomy, Rights and Children with Special Needs: A New Paradigm?

Working Paper 6

Literature Review: Autonomy, Rights and Children with Special and Additional Support Needs

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Sheila Riddell
Centre for Research in Education Inclusion and Diversity
University of Edinburgh



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Introduction

In the post-war period in both England and Scotland, the field of special education was dominated by the policy frameworks of professionalism and bureaucracy, in which professionals made educational decisions, and parents and children were accorded few rights (Riddell & Weedon 2010). By the time of the Warnock reforms of the 1970s, parents were recognised as playing a partnership role, but were certainly not regarded as having equal decision-making powers (Riddell & Brown, 1994, republished 2019). Policy divergence between England and Scotland began with the English educational reforms of the 1980s and 1990s, informed by marketization, managerialism and consumerism, which led to a growing focus on parental rights as the driver of the education market. For example, the establishment of the Special Educational Needs Tribunal in 1994 boosted the rights of English parents to challenge official decisions. In Scotland, change came about rather more slowly. Under the terms of the Education (Additional Support for Learning) (Scotland) Act 2004, new dispute resolution mechanisms were made available to parents and young people, including the Additional Support Needs Tribunal, independent adjudication and mediation. As noted by Harris (2009), at this point in time children's rights scarcely featured on the policy horizon.

The emphasis on children's rights in recent policy and legislation in the field of SEN/ASN has been driven by a number of national and international developments, in particular the UN Convention on the Rights of the Child (UNCRC) (1989). Article 2 requires states parties to respect and ensure the rights of the child, while Article 3 states that the best interests of the child shall be the primary consideration in all actions concerning a child. Of particular relevance to education is Article 12, which states that every child capable of forming a view has the right to express that view on all matters of concern to him or her, including in the content of administrative and judicial processes. The application of the best interests standard, mentioned on nine occasions in the Convention, means that the rights of the child are caveated rather than absolute (Freeman, 2007; Cockburn, 2013). The Convention also qualifies an absolute commitment to children's rights by stating that 'due regard' must be paid to the child's views in the light of his/her age and maturity, taking into account local resources and cultural norms. At UK level, the focus on children's involvement in decisionmaking is also driven by the wider personalisation of welfare agenda, which may be seen as a form of empowerment, or as a smokescreen for creeping privatisation and shrinking public expenditure.

The operationalisation of the rights of children with SEN/ASN raises both practical and conceptual issues. For example, questions arise concerning the nature of choices which children of different ages and with a range of difficulties are able to make, particularly in school contexts where pedagogy and curriculum have traditionally been determined by adults. Such questions also occur in relation to children's involvement in dispute resolution, where disagreements over resources have traditionally involved adults rather than children. Finally, methodological and ethical issues arise in relation to children and young people's involvement in research aimed at assessing the nature of their participation. At the heart of

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¹ Children and Families Act 2014; Children and Young People (Scotland) Act 2014; Education (Scotland) Act 2016

our research is the question of whether it is possible (and/or desirable) for a child or young person with SEN/ASN to operate as an autonomous social actor in order to achieve desired social goals.

This thematic literature review is intended to inform our research on the implementation of new rights-based legislation in England and Scotland² and should be read alongside other Working Papers https://www.ed.ac.uk/education/rke/centres-groups/creid/projects/autonomy-rights-sen-asn-children/working-papers. The paper begins with a brief overview of the literature on children's rights, citizenship and autonomy, along with commentaries on recent international conventions to promote the rights of children and disabled people. Education policy is placed within the wider context of the individualisation of services, which may be seen as a form of empowerment or as an erosion of post-war collective rights. The literature on tensions between needs and rights in education is discussed, along with the relationship between parents' and children's rights. Findings are reviewed of empirical studies on children's involvement in everyday life in schools and classrooms, the production of education planning documents (e.g. EHCPs, CSPs and IEPs) and dispute resolution processes. Finally, on-going debates about rights and autonomy are discussed.

Rights and citizenship

Rights and citizenship are closely linked concepts, since citizenship is based on the enjoyment of specified rights in particular societies. Much writing on citizenship draws on T. H. Marshall's lecture on citizenship and social class (Marshall, 1950/1992). Marshall identified three dimensions of rights, which developed chronologically and are seen as essential components of citizenship in developed countries. These are civil rights, initially developed in the eighteenth century; political rights which developed in the nineteenth century; and social rights which developed in the twentieth century. Marshall, a strong proponent of the post-war welfare state, argued that civil, political and social rights are interconnected and, taken together, these rights mitigate, but cannot fully eradicate, inequalities in status and wealth. Marshall's ideas on citizenship and rights have been criticised on the grounds that they focus on the position of men rather than women and adopt a universal rather than culturally specific understanding of rights. In addition, while recognising education as a key social right, Marshall regarded children as proto- adults rather than full citizens. In his view, children have a right to education (and other types of welfare), because this is essential to their becoming a fully developed adult. Education is:

... trying to stimulate the growth of citizens in the making. The right to education is a genuine social right of citizenship, because the aim of education during childhood is to shape the future adult. Fundamentally it should be regarded, not as the right of the child to go to school, but as the right of the adult citizen to have been educated. (Marshall, 1950/92, p.16)

If, as argued by Marshall, social rights are necessary to the enjoyment of civil and political rights, then the promotion of additional civil rights for children at a time of austerity might

² This literature review informs the ESRC-funded project *Autonomy, Rights and Children with Special Needs: A New Paradigm?* (ES/P002641/1, conducted by researchers at the Universities of Edinburgh and Manchester between July 2017 and July 2019.

be seen as a distraction from the real issues threatening children's well-being, that is the erosion of their social rights. Cockburn (2013) argued that it is counter-productive to boost children's legal rights if, at exactly the same time, resources are being withdrawn from education and social welfare. The relationship between legal and social rights is an important issue in our research.

Autonomy rights of children: legal and moral principles

Onora O'Neill (1988), chair of the EHRC from 2012 to 2016, has argued that, although children should be seen as rights-bearers, their vulnerability and need of adult protection makes them inherently different from adults. Whereas adults are expected to make choices and accept the consequences, children are unable to understand the implications of choices made at an early stage in their lives, and therefore adults must always mediate children's expressed wishes with a view to determining what is in their best interests. In addition, children lack the power to use formal mechanisms to enforce their rights. For these reasons, children should not be expected to operate as fully autonomous rights-holders. O'Neill begins her seminal paper of 1988 by acknowledging the apparent advantages of according children full citizenship rights:

We may begin with a reminder of the appeal and importance of thinking in terms of children's rights. Children easily become victims. If they had rights, redress would be possible. Rather than being powerless in the face of neglect, abuse, molestation and mere ignorance they (like other oppressed groups) would have legitimate and (in principle) enforceable claims against others. (O'Neill, 1988, p.445)

Rather than expecting children to ensure that their rights are met, O'Neill argues the case for 'setting up institutions that can monitor those who have children in their charge and intervene to enforce rights.' (O'Neill, 1988, p. 445).

This type of argument tends to be characterised as paternalistic by advocates of the children's liberation movement (<u>Farson, 1974</u>), who argues that children should be regarded as fully autonomous rights holders with similar status to adults. Along similar lines, Holt suggests that:

The rights, privileges, duties, responsibilities of adult citizens be made available to any young person of whatever age who wants to make use of them' (1974, p.15).

Article 12 of the UNCRC promotes a gradualist approach, so that the rights enjoyed by children are gradually increased in relation to their age and maturity. Rather than arguing that all children should have exactly the same rights, the UNCRC notes that, as children mature, the rights accorded to them should gradually increase:

States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (UNCRC, 1989).

However, as noted by Archard (2015), there is an asymmetry in the treatment of children and adults. All adults, other than those who are deemed incapable, are permitted to

exercise autonomous choices irrespective of whether these are wise or not. By way of contrast, children are required to demonstrate capacity in order to have their views taken into account, and in some areas (for example, voting) are judged as a group to be ineligible. By virtue of their age, adults are always in a position to make judgements about whether children's views are in accordance with their 'best interests', even if the adult's beliefs and judgements may objectively be against a child's interests. With reference to legal decision-making in health in the UK and child protection in Norway, Archard and Skivenes (2009) agree that the child's views are not authoritative, but at the same time should not be treated as merely consultative, as argued by Brighouse (2003).

Tisdall (2018) notes that the UNCRC has encouraged many countries to strengthen children's rights, but difficulties in implementing participation rights have frequently arisen as a result of the requirement to take account of a child's competence and capacity. In the context of family law proceedings, she unpicks the concepts of competence and capacity, arguing that these are generally seen as inherent to the child, rather than contextual and relational. Ultimately, she argues that children's participation rights are likely to be strengthened by alternatives, such as new ideas about how to recognise and support people's legal capacity within the UN Convention on the Rights of Persons with Disabilities. Despite the strength of these arguments, our fieldwork to date highlights the challenges in supporting disabled children with little or no speech to participate in decision-making.

Despite the emphasis on children acquiring rights at different ages according to their degree of understanding, many developed countries still use chronological age in a somewhat arbitrary manner to determine rights and responsibilities. In the UK, for example, young people normally have the right to vote at the age of 18, but in the Scottish referendum on independence in 2014, the voting age was reduced to 16. In the opposite direction, the age of criminal responsibility in Scotland was recently changed from 8 to 12. In other areas, subjective assessments of competence and capacity are used to decide which children can exercise their rights of participation. For example, in medical law the concept of Gillick competence³ is used to decide whether a child under 16 years of age is able to consent to his or her own medical treatment, without the need for parental permission. Broadly, if a child is judged to have sufficient understanding and intelligence to fully comprehend the treatment which is proposed, then parental consent may not be required for particular procedures. At the same time, the court may over-rule a child's power to consent to or refuse medical treatment. Foster (2009), in his critique of the principle of autonomy in medical ethics and law, suggests that '... autonomy flounders when it comes to the question of the treatment of and withdrawal of treatment from children' (Foster, 2009, p. 121). In the use of the best interests test, Foster argues that the law is 'appropriately paternalistic'. He explains:

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³ The Gillick case arose as a result of a health department circular which stated that a doctor could prescribe contraception to a minor without parental consent. In 1985, Victoria Gillick mounted a legal challenge against West Norfolk and Wisbech Area Health Authority on the grounds that parents retained the right to determine what was in the best interests of a child under the age of 16. Lord Scarman determined that 'As a matter of Law the parental right to determine whether or not their minor child below the age of sixteen will have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed'.

The child's view of where its best interests lie should of course be ascertained, and the older the child is, the greater the weight they will have, but best interests, say the courts, are an objective matter: the child's views are pertinent but certainly not determinative (Foster, 2009, p.123).

Debates around autonomy, competence and capacity have particular resonance in the field of medical ethics because of their implications for matters of life and death. At the same time, these issues are highly relevant to other field of social decision-making, including family law (<u>Tisdall, 2018</u>), youth justice (<u>Hollingsworth, 2013</u>) and education. Children as rights-bearers are not only constructed in law, but also as users of welfare services, and in the following section I discuss children as social services users.

New public management and the construction of the child as consumer

Since the 1980s, there has been a general move across the UK to recast citizens, including children and young people, as consumers of public services with responsibility for managing their own welfare. The rise of the citizen-consumer is an intrinsic element of New Public Management (NPM), which characterised the public sector as intrinsically wasteful and self-serving. In order to promote effective and efficient service delivery, the disciplines of the market needed to be applied to the public sector. Citizens and clients were recast as consumers and public service organisations were recast in the image of the business world (Newman & Clarke, 2009). As a result of consumer choice, it was envisaged that popular services would flourish while less effective and unpopular services would wither on the vine. In order for the public sector market to work efficiently, consumers needed access to reliable information, potentially a problem for some groups such as children, old people and those with learning disabilities.

Direct payments provide an example of the application of the principles of NPM to the field of social care. Direct payments are funds paid by local authorities to disabled individuals and other social care service users to purchase their own support. They may be seen as an important means of empowering individuals to act as 'co-producers' of support services (Priestley et al., 2006), determining what support is needed, where it is delivered and who is involved in its provision. Alternatively, direct payments may be seen as a form of 'creeping privatisation' (Pearson et al., 2005, mistrusted by public sector trades unions and 'Old Labour' local government on the grounds that the profit motive should not be involved in the delivery of publicly-funded services. Questions continue to be raised about whether direct payments are an appropriate form of welfare provision for disabled people and 'community care' groups, or whether some individuals, for example younger or older disabled people living in socially disadvantaged circumstances, may find it difficult to operate as critical consumers. Particular issues arise in relation to disabled children and young people, who are unlikely to manage the payment themselves, but rely on a parent or carer to help them do this. The dangers of exploitation by other family members or carers may be particularly acute in relation to younger people, and it is possible that any empowerment achieved may be for the adults surrounding the child or young person, rather than the disabled child (Riddell, 2008; Riddell et al., 2005).

Individual budgets for adults in England and Wales were developed in the mid-2000s, bringing together resources from a number of funding streams, including local authority social care budgets, community equipment, housing adaptations, housing related support through the Supporting People programme, the Independent Living Fund and Access to Work from the Department for Work and Pensions. More recently, individual budgets for disabled children and young people have been developed. In England and Wales, the Children, Schools and Families Act (2014) states that if there is an Education Health and Care Plan, the young person (or child's parent) has the right to have a personal budget prepared if he/she requests one, and may also give consent to direct payment.

In Scotland, the Scottish Government employed the term Self Directed Support (SDS) to develop distinctive policy goals focusing on citizen empowerment, public health and community cohesion. The Social Care (Self Directed Support) (Scotland) Act 2013 was implemented in 2014, just as austerity measures were beginning to bite. Between 2010 and 2014, Scottish public sector spending was reduced by 11 per cent, with a 7 per cent cut in local authority spending and a 37 per cent cut in capital spending. Cuts in social welfare spending have continued, reaching a peak in 2016 (Pearson et al., 2015). Currently, children and young people, or adults acting on their behalf, are entitled to be holders of Self Directed Support budgets in order to purchase social care including lifelong learning services. The roll out of individualised services (Direct Payments and Self Directed Support) has coincided with reductions in social security, leading to question about whether the personalisation agenda should be seen as a strategy to manage cuts and make them more palatable. Resources could be targeted on those able to operate as successful citizen-consumers, while less astute customers could be left to bear the brunt of public sector cuts. As our analysis of Scottish data demonstrates (Carmichael & Riddell, 2017), those from less advantaged backgrounds are more likely to be identified as having ASN, but less likely to receive statutory support plans.

To summarise, the delegation of welfare budgets to individuals provides a clear expression of the consumer-citizen model in practice. In addition, responsibility for the nature and quality of SEN/ASN services is increasingly being delegated to service users. In England and Wales, local authorities have new duties under the 2014 Act to consult with children and young people about education and social care provision and to publish the outcomes of consultation with children and young people regarding the local offer and the local authority's response. Information about the local offer and advice and information services must be published in a format which is accessible to children and young people with SEN. In Scotland, although local authorities have a duty to ensure that information about services for children with ASN is available in local schools, requirements with regard to information and consultation are less stringent. Scotland, however, has gone further than England in terms of the new rights accorded to children above the age of 12 who are deemed to have capacity. Scottish children with ASN have the right to consent to the sharing of personal data, to request a particular type of assessment or a statutory support plan and to take a case to the tribunal.

Overall, it would seem that in both England and Scotland, efforts have been made to construct children and young people as autonomous citizen-consumers, reflecting the growing dominance of a liberal and individualistic understanding of rights. However,

difficulties in realising children's participation rights are not just to do with doubts about children's capacity and competence, but also to the existence of parallel and competing bodies of legislation with different provisions and underlying principles. The various manifestations of these tensions are reviewed in the following sections.

Education and equality legislation: underpinning conceptualisations

In both England and Scotland, children's rights in education are underpinned by overlapping education and equality legislation, described in the 2002 Disability Rights Commission's Code of Practice as a 'jigsaw' of legal support (Disability Rights Commission, 2002). In 2001, the Special Educational Needs and Disability Act (SENDA) was passed, extending the provisions of Part IV of the Disability Discrimination Act (DDA) to education. Because of devolved education legislation, the provisions of SENDA did not apply in Scotland, although the amendments to Part IV of the DDA did. The DDA is now subsumed within the Equality Act 2010, but many of the contradictions and tensions between education and equality legislation persist (Blair & Lawson, 2003; Riddell, 2003; Norwich, 2014). These include differences in definitions of disability and special/additional support needs; duties applying to school and post-school educational providers; routes of redress; and provisions applying in the four nations of the UK. Of great importance are the different philosophical underpinnings of the two bodies of legislation. Whereas disability equality legislation aimed to establish comprehensive and enforceable civil rights, education legislation has (at least until recently) been less focussed on rights and more focussed on the duties of service providers to identify and meet needs. Norwich (2014) argues that although the Children and Families Act (2014) claims to introduce a radically new system, in reality the new system is very like the old one, and previously unresolved issues continue to pose problems. In particular:

The opportunity was also lost to integrate the SEN and disability legislative systems, so perpetuating the confusion and waste of two different systems. (Norwich, 2014, p. 425)

Under the different bodies of legislation, it remains the case that in both England and Scotland, it is possible for parents, young people and (in Scotland only) children to pursue different routes of redress simultaneously. For example, a parent concerned about inadequate assessment or provision could use two separate routes of legal redress under education and equality legislation, with both cases being dealt with by the tribunal.

Wellbeing and rights in education policy and legislation

A further source of tension concerns bodies of legislation based on conceptions of wellbeing/needs or rights, concepts which are often used synonymously but have different 'conceptual and academic genealogies' (<u>Tisdall, 2015a</u>). Tisdall notes that the Children and Young People (Scotland) Bill was initially framed as a dedicated Children's Rights Bill which would deliver the most advanced provision in relation to children's rights in the UK. In the event, the Government produced a consolidated bill which was designed to bring together children's rights with proposals for children's services. Tisdall's analysis of the parliamentary debates and submissions around the Children and Young People (Scotland)

Act 2014 shows that initial attempts to foreground rights were gradually replaced by an emphasis on wellbeing through the assessment of needs. Part 1 of the Act placed new duties on Scottish Ministers and local authorities to implement children's rights as set out in the UNCRC, and to report to the Scottish Parliament on a triennial basis. Later sections of the Act were organised around children's wellbeing, with eight wellbeing indicators used to inform *Getting it Right for Every Child* (GIRFEC) assessments. Parts 4 and 5 of the Act stipulated that a Child's Plan should be opened for children whose wellbeing was judged to be in jeopardy, and that each child should have a Named Person to co-ordinate service provision and share information with other professionals. From a children's rights perspective, Tisdall suggests that the Act provides little opportunity for children, young people or parents to challenge the actions of duty-bearers, for example, in relation to the sharing of confidential information; the identity of the Named Person; the assessment of needs against SHANARRI indicators; proposed provision.

Tisdall (2015b) argues that evidence and debates on the Children and Young People (Scotland) Bill tended to emphasise problems with allowing children access to litigation to enforce their rights, which was seen to be at variance with the Scottish social welfare tradition. It was argued that the UNCRC was an aspirational document which did not need to be underpinned by legal routes to redress. By way of contrast, there was considerable enthusiasm for the extension of the 'general welfare duty' by local authority managers who referred to Highland Region's positive experience of implementing GIRFEC. The concept of wellbeing was not defined in the legislation, and the SHANARRI indicators were assumed to include a definition of wellbeing, whereas they are in fact a set of indicators to be used in assessment. A spokesperson for Barnardo's Scotland, giving evidence to the Education and Culture Committee, commented:

There is a danger that, for those who are coming to it fresh, 'wellbeing' sounds a rather fluffy, ill-defined term. In fact the definitions of wellbeing are very clearly established around what are called the SHANARRI indicators. The tools that have been developed have been widely accepted across agencies. Having a common language is a real benefit (Martin Crewe, Barnardo's Scotland, ECC, 17.9.13, 2799).

Evidence presented to the Education and Culture Committee made clear that assessments of wellbeing were based on professionals' rather than children's or parents' understandings, with only limited consultation with children and young people. In addition, those giving evidence to the committee emphasised that assessments of need must take into account local resource availability. Mike Burns, a spokesperson from the Association of Directors of Social Work, suggested that: '... professionals need to work together to be clear about how a child's needs will be best served by the local resources that are at their disposal' (ECC, 3.9.13, 2699).

Particularly heated debates arose around the role of the Named Person, with concerns expressed around infringement of parents' and children's rights to confidentiality. The Scottish Government conceded that the information holder should have regard to children's and young people's views, so far as is reasonably practicable, taking into account the child's age and maturity. However, the Government argued that there can be circumstances where children's wish for confidentiality could legitimately be breached. In the event, a judicial review was launched against the Named Person's provisions of the legislation on the

grounds that they breached rights to privacy and family life under the European Convention on Human Rights. The appeal was dismissed by the Court of Session in Edinburgh in 2015, but upheld by the Supreme Court in 2016. At the time of writing, Parts 4 and 5 of the Children and Young People (Scotland) Act 2014 have yet to be commenced.

Over time, Tisdall argued, parliamentary debates on the Children and Young People Act show increasing reference to wellbeing and decreasing reference to rights, driven largely by fears of children and young people engaging in litigation. Two years later, the enactment of the Education (Scotland) Act 2016 was heralded by the Government as placing Scotland in the international vanguard in the realisation of children's rights. As discussed in our review of policy and legislation (Harris, 2018) and analysis of Scottish key informant perspectives (Riddell et al., 2018), there continue to be major tensions between local authority officers' desire to promote wellbeing principles, and those adopting a children's rights perspective. Particularly controversial is the requirement that, before a child aged 12-15 can exercise a right, they must seek permission from the local authority, which will decide whether the child has capacity, and whether exercising the right would have a detrimental effect on the child's well-being.

Morrow and Mayall (2009) suggest that both in the UK and internationally there is a tendency to focus on well-being rather than rights because the former concept is more susceptible to measurement against a range of indicators. As an example, Morrow and Mayall critique the use of secondary datasets to measure well-being as used in the UNICEF Innocenti Report titled *Child Poverty in perspective: an overview of child well-being in rich countries* (UNICEF, 2007). The report placed the UK's children at the bottom of the league table of rich nations on their average score across six dimensions, including emotional well-being and happiness. Morrow and Mayall argue that the report exemplifies a deficit approach to the study of children's lives, with a focus on negative experiences. Its findings are often presented as scientific 'fact' in press reports, despite problems with definitions of well-being.

Tensions between needs and rights in ASN

In Scotland, tensions between needs and rights are evident in the evolution of SEN/ASN policy since the post-Warnock reforms of the early 1980s, which for the first time accorded parents the role of partners in their child's education (Riddell & Brown, 1994/2019). Discussions around the ASN reforms of 2004 indicated significant tensions between those wishing to protect professional power, and those arguing that parental rights should be boosted. Riddell and Weedon (2010) analysed responses to two stages of consultation on the Education (Additional Support for Learning) (Scotland) Act 2004 (Scottish Executive, 2001; 2003), referred to here as the ASfL legislation. Riddell and Weedon identified contrasting positions adopted by local authority offers and educational psychologists on the one hand and parents on the other. The former argued for the abolition of statutory support plans (Records of Need) on the grounds that these were overly bureaucratic and accorded too much power to parents. They believed that professionals should have the power to identify and meet children's needs without external interference. Parents, in contrast, felt that statutory support plans were vital in ensuring that additional resources were allocated, provision reviewed and routes of redress made available.

The 2004 ASfL legislation was hailed by the Scottish Executive as a major step towards the full social inclusion of children with ASN by attaching resources to individual children to help them overcome challenges and barriers. However, as noted by Newman and Clarke (2009), it is very important to look at:

... how grand designs get translated into politics, policies and practices. In such processes we may begin to see the contradictory and antagonistic effect of different social forces, different problems to be overcome or accommodated, different local or national contexts that bend strategies into new forms ... (Newman & Clarke, 2009, p. 18).

Analysis of the impact of the ASfL legislation indicated ongoing resistance by local authorities to aspects of policy intended to increase parental rights⁴. Surveys with Scottish parents and local authority officers' perceptions of the new dispute resolution routes (Riddell et al, 2010; Weedon & Riddell, 2009). Parents supported the new Tribunal procedures on the grounds that they provided a clear and (relatively) enforceable route of redress. They were less keen on independent mediation on the grounds that recommendations were unenforceable and parents were in danger of mediating away their rights. Complaints procedures at school and local authority level were criticised, on the grounds that teachers and local authority officers were unlikely to listen to parents' concerns unless forced to do so. By way of contrast, local authority officers were highly critical of the tribunal on the grounds that it ceded too much control to 'vexatious' parents and impinged on local authority responsibility to reach impartial judgements on resource allocation.

The struggle between interest groups supporting either a needs or a rights-based approach continues, as illustrated by the responses to the 2008 consultation on amending legislation (Scottish Government, 2008). Local authorities, having ceded little in the way of parental rights (Harris, 2005), continued to press for a much wider overhaul of the legislation, including abolition of CSPs:

The production of the CSP is procedurally complex and formal. By its nature, it is driven by official letters and procedure-driven meetings. The need to have documents written in a standard defensible style has already resulted in a CSP style of writing which, like the language of its predecessor the Record of Needs, acts as a barrier to plain communication. It is very difficult to detect any additional benefit impact on interagency working either from the CSP process or the documents themselves. (Local authority officer response to consultation on the Education (Additional Support for Learning) (Scotland) Bill 2008).

In contrast, a response from a parents' advocacy organisation documented the ways in which local authorities were subverting the legislation, including restrictive interpretation of qualification criteria for a CSP, failing to respond to requests for adjudication and failing to implement the recommendations of adjudication and the ASNTS.

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⁴ An ESRC funded project on dispute avoidance and resolution in ASN/SEN (RES-062-23-0803) used analysis of official statistics, key informant interviews, surveys and family case studies to explore the responses of different social actors to the new measures.

The 2009 amendments to the ASfL legislation, far from abolishing statutory documents and duties, appeared to strengthen the rights of particular groups of children with ASN. For example, children looked after by the local authority were deemed to have ASN, unless assessed otherwise by the local authority and a duty was placed on local authorities to assess which looked after children required a CSP. However, following the implementation of the 2009 amendments, questions were raised about the extent to which local authorities were complying with legislative requirements. The response from Who Cares Scotland to the Scottish Government's 2016 Governance review stated:

Young people deemed to have additional support needs have a statutory right to a Coordinated Support Plan (CSP) ... It is our belief that this legislation has the potential to make transformational change in enabling young people to achieve whilst at school. An effective and appropriate CSP better places young people in their pursuit of further or higher education. Our advocacy experience informs us that very few care experienced young people are aware of being assessed by their local authority. This anecdotal evidence is supported by freedom of information requests, submitted by Govan Law Centre, which revealed that not all local authorities are meeting the statutory obligation of assessing all their looked after young people, with only 2.9% having a CSP. This is further supported by information from the Centre for Excellence for Looked After Children in Scotland (CELSIS) who report that feedback from the workforce suggests authorities are often not assessing looked after children for their suitability for a CSP, sometimes due to not understanding that they have a right to this under the legislation and other times, perhaps more concerningly, that they don't have the resources available to meet the needs that a coordinated support plan would identify. (Who Cares Scotland, 2016)

To summarise, in the field of ASN in Scotland there is a growing policy cleft between the children's rights and professional communities (see also *Working Paper 5 Analysis of Key Informant Interviews: Scotland*)

http://www.docs.hss.ed.ac.uk/education/creid/Projects/39 ii ESRC SENChildren WP 5.pd f (Riddell et al., 2018)

Parents' and children's rights

In addition to disagreements between advocates of well-being/needs and rights, there are also tensions between parents' and children's rights, with the former taking precedence until recently. Debates in this area are influenced by the disability movement's insistence that the voices of disabled children and adults must be heard directly, rather than mediated by third parties, such as professionals, voluntary organisations, parents and carers.

Parents have traditionally been constructed as the bearers of educational rights (Harris, 2009; Lundy, 2007, 2012), a principle reflected in the Education Act 1944 (and the Education (Scotland) Act 1945) which states that 'pupils are to be educated in accordance with the wishes of their parents'. Education in accordance with parental wishes is also a key element of SEN/ASN policy, accompanied by an aspiration that children's views will be sought, although not necessarily acted upon. Harris (2009) notes that tensions between parents and children's rights are evident in international instruments such as the European Convention on Human Rights (EHCR), which states, in Article 2 of the first protocol, that 'noone shall be denied the right to education'. This is followed by a commitment to the principle that the state must 'respect the right of parents to ensure such education and

teaching in conformity with their own religious and philosophical convictions'. It is thus assumed that parents' religious and philosophical convictions take precedence over those of their children. This privileging of adult rights is characterised as a 'parent-oriented approach' (Fortin, 2003).

Harris (2009) argues that parental choice was used in the 1980s and 90s as the principal driver of the education market. Measures to facilitate parental rights to choose out-of-catchment schools were introduced in all four nations of the UK, with Scotland and England periodically 'leapfrogging' each other in terms of extending parental choice. Despite an overarching presumption of mainstreaming in both jurisdictions, parents of children with SEN/ASN were accorded the right to choose between mainstream and special sectors and between independent and maintained schools, although a number of caveats applied which effectively limited choice. These included the right of the local authority to refuse a placing request if it would involve unreasonable public expenditure, or if it would be detrimental to the education of the child in question or other children in the class. The Education (Scotland) Act 2016 does not accord children with ASN the right to make a placing request on the grounds that this might clash with parental rights and be disruptive to family life, again signalling that, at least in some areas, parental rights trump children's rights.

Over the past three decades, however, our research has demonstrated that in practice the exercise of rights by parents is strongly associated with a range of other variables, particularly social class. Parents from more socially advantaged backgrounds are likely to be familiar with the 'rules of the game', enabling them to work the system in their favour. This is reflected in the fact that children from less advantaged areas are more likely to have ASN identified than those from more advantaged areas, but are less likely to have CSPs. (Riddell & Weedon, 2016; Carmichael & Riddell, 2017). Research on encounters between parents and professionals shows that parents from middle class backgrounds are able to adopt the same cultural register as professionals and to deploy social networks to support their efforts to access resources and ensure that placing requests are successful (Riddell & Weedon, 2017). They understand the symbolic significance of different disability categories, so that stigmatising labels, such as social, emotional and behavioural difficulties, are attached more frequently to children from poorer backgrounds. By way of contrast, children from more advantaged backgrounds are likely to receive 'labels of forgiveness' (Slee, 1995), such as dyslexia or ADHD, which exculpate parents, children and school, identifying the problem as medical or neurological condition for which no one is to blame.

In summary, at least until recently, parental rights have generally trumped those of children and parents from more socially advantaged backgrounds have been particularly successful in winning additional resources. Despite the evident strength of (middle class) parental agency, the disability movement has questioned the motives of parents and carers who act as advocates for their children. However, Ryan and Runswick-Cole (2008) are critical of what they see as the downplaying of parents' 'special competence'. The role of activist mother, they suggest, has been largely overlooked, resulting in the side-lining of children's most determined advocates:

Mothers of disabled children have occupied a complex, contradictory and marginal position within both disability studies and the disabled people's movement. This

marginalisation is related to the (often) non-disabled status of the mothers which propels them into the difficult and contentious debates about the role of non-disabled people within the lives of disabled people and within disability studies. This tension is further complicated by the relationship between mothers and their children in which the actions of mothers have been interpreted as constraints within their children's lives, limiting their opportunities and aspirations. (Ryan & Runswick-Cole, 2008)

Ryan and Runswick-Cole note that parents are often accused of embracing a medical model of disability by seeking a diagnosis such as autism. However, this could be understood as pragmatically seeking the type of capital which gives access to services and resources. There is a significant body of literature, they suggest, which 'interprets the experiences of parents of disabled children as either delusional or is couched in terms of grief, loss or denial (or self-interest)'. They also note that mothers, more than fathers, are the subjects of societal scrutiny and surveillance in relation to their parenting skills, and may be blamed for producing a dysfunctional child. We are reminded that until the 1960s it was not unusual to blame the 'refrigerator mother' for the behaviour of autistic children.

Ryan and Runswick-Cole conclude by suggesting that more studies of parenting disabled children are needed, taking into account type of impairment, gender, ethnicity, age and social class. In addition, in line with arguments made by Tregaskis (2004), they suggest the need to identify points of common interest between disabled and non-disabled people, as a basis for forming 'alliances for change'.

Children's participation in schools and classrooms

As noted by Rose (1989/99), childhood remains the most intensely governed sector of personal existence, where social regulation may have little to do with the realisation of rights, and far more to do with controlling those who may challenge the social order (Rose, 1989/99). Much of the literature on children's rights in education provides a depressing picture of schools as rule-bound organisations, where children are disciplined to accept social and cultural norms. Attitudes to school are strongly related to social class, with children from poorer backgrounds finding school 'controlling and boring; somewhere they tried to spend as little time as possible' (Sutton, 2007, p. viii). Wyness (2000) notes that 'the timetable and the curriculum are overlaid with codes of conduct and modes of self-display, with rules and regulations separating children from decision-making' (Wyness, 2000, p. 90). Mayall (2002, p.101) describes schools as 'profoundly undemocratic'. Citizenship education as currently practised has been criticised for being ambiguous about rights, tokenistic and controlled by adults (Lockyer, 2003). Institutions such as pupil councils have also been criticised for a tendency to include favoured and conforming pupils, and permitting discussion of a narrow range of topics approved by adults (Weller, 2009).

On a more positive note, a survey of attitudes to education held by 845 first year pupils in English secondary schools suggested an 'almost universal' commitment to the value of education, but, for a minority, an ambivalence about the experience and relevance of schooling for them (Croll et al., 2008). Small scale qualitative studies have reported similar findings. For example, research on children's experience of an inclusive primary classroom

in the north east of England (<u>Adderley et al., 2015</u>) found that many children could not find anything negative to say about their school experience, although they did identify four areas which might contribute to children's feeling of inclusion or exclusion: unfairness, teachers shouting, loneliness and seating plans.

Although children and young people with SEN/ASN have been accorded greater rights, it is unclear whether schools provide the type of environment which is conducive to the realisation of these rights, particularly for children with challenging behaviour/SEBD. A study of school exclusion and alternative educational provision in Wales (McCluskey et al., 2015; McCluskey et al., 2016) demonstrated that boys with special educational needs from poorer backgrounds were disproportionately more likely to be excluded from school compared with pupils who do not share these characteristics. The process of exclusion takes little account of pupil voice, and post-exclusion educational provision is often inadequate. Similar issues have been identified in Scotland (Riddell & McCluskey, 2012).

Particular problems in school and classroom participation are also likely to be experienced by those with complex difficulties. In their study of participation in decision-making by disabled children and young people in Northern Ireland, McNeilly et al. (2015) observed that children and young people with complex needs experienced an environment and daily routines which were tightly controlled by adults. In such cases, they acknowledge that children and young people may not be able to act as the 'main deciders' in relation to current and future education, health and social care plans. However, they suggest that the use of more sensitive communication methods and accessible information for children, young people and adults will ensure greater recognition and respect.

Franklin and Sloper (2006; 2009) also highlight the mismatch between the legal entitlements of disabled children and young people and the extent to which these rights are realised in practice. They note that the Children Act guidance and regulations relating to disabled children make it clear that this group cannot be assumed to be incapable of sharing in decision-making, and arrangements must be made to establish their views. For people aged over 16, the Mental Capacity Act 2005 states that a person must be assumed to have capacity unless it is established that they lack capacity. In addition, Article 13 of the CRC grants children the right to receive information and express their views in a variety of forms. Their research investigated disabled children and young people's participation in decisions on social care in six social services departments in England. In addition to a survey, interviews were conducted with professionals, parents and disabled children and young people. Verbal interviews were conducted with children in the sample, supplemented by alternative techniques, including Talking Mats, for those with complex needs and communication difficulties. The researchers found that even though authorities had policy and procedures documents which stated that children should be involved in decisionmaking, these in themselves did not change practice, and in most cases adults, rather than children, set objectives. The results of the research indicated a need for developments in the following areas:

 A broader understanding of the meaning of the term 'participation' for disabled children with an emphasis on the validity of children participating at whatever level is appropriate;

- Recognition that disabled children communicate in mediums other than speech, including recognition that observation can be a valid means of ascertaining the views of some disabled children with profound and multiple disability;
- An individualised approach to participation, with attention placed on children's communication methods where appropriate; more attention and resources placed on developing the participation of a wider range and number of disabled children;
- More recognition of the resources, time and support required to facilitate successful participation;
- More training, skills development and support for staff and children;
- The development of more participation working to facilitate participation;
- Opportunities for those engaged in disabled children's participation to share information, support and skills development, both locally and nationally;
- More emphasis placed on feedback for those involved;
- The importance of ensuring that in individual decision-making, children's voices are taken into account in developing and reviewing care plans, and that where views cannot be acted upon, it is explained to the child and family why this is so;
- In-service development initiatives, ensuring that mechanisms are put in place for children's views to be fed into decision-making and, again, and that children are kept aware of what is happening, and the reasons why developments may not be taking place;
- The need for monitoring and evaluation of participation to feed into future development of practice.

Lundy (2007) suggests that pupil voice may simply be deployed as a 'flavour of the month' concept, rather than being seen as 'a permanent, non-negotiable human right'. Drawing on research commissioned by the Northern Ireland Commissioner for Children and Young People on the implementation of Article 12, Lundy suggests that decision-makers need to focus on four elements of provision:

- Space: Children must be given the opportunity to express a view
- Voice: Children must be facilitated to express their views
- Audience: The view must be listened to
- Influence: The view must be acted upon, as appropriate.

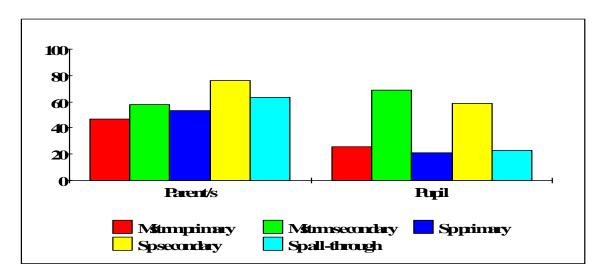
A number of researchers have raised doubts about the requirement to genuflect to the idea of pupil voice, regardless of whether this is being genuinely sought and acted upon (Scanlon et al., 2016; Lewis et al., 2007; Howell, 2017). McKay (2014) suggests that the requirement for the child to express a view may be experienced as a source of pressure and shame, and that advocacy services may only present views which are deemed to be sensible and acceptable. Lewis (2010) argues that rather than focusing uncritically on 'child voice' as 'a good thing', researchers should also pay attention to child silence and its significance.

Children's participation in educational planning

There has been a growing expectation across the UK that children and parents will routinely be involved in statutory and non-statutory educational planning. Research reported by Kane et al. (2003) investigated the involvement of parents and children in the drawing up and

reviewing of Individual Educational Plans (IEPs) in Scotland, in light of the requirement that IEPs will be drawn up for all children with ASN, and that parents and children will be involved in specifying and reviewing short-term and long-term targets. A survey of special and mainstream schools in Scotland showed that parents were more likely to be involved than pupils. Pupils in mainstream and special primary schools were the least likely to be involved (see figure below)

Key individuals (parents and pupils) always involved in the development of IEPs by sector and age group (percent)



Source: Kane et al. (2003)

Similar findings emerge from an analysis of Education Health and Care Plans (EHCPs) in England (Palikara et al., 2018). The researchers examined the contents of 184 EHCPs produced for children with disabilities and/or SEN in the Great London area. Despite the legal requirement to involve children and young people, the researchers found high levels of variability in the way the voices of parents and children were captured, including the methods used to ascertain their views. As in the Scottish study of IEPs, children with SEN in mainstream schools were more likely to be involved than their peers in special schools.

Children's participation in dispute resolution

The new legislation and Codes of Practice for England and Scotland (<u>DfE & DoH, 2015</u>; <u>Scottish Government, 2017</u>) emphasise the importance of involving children and young people in dispute resolution⁵ as far as is practicable. In both jurisdictions, routes of redress and eligibility criteria are extremely complex. In England, parents and young people over

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⁵ The routes to resolving SEND disagreements in England are as follows: Informal discussion at school & LA level; SEND Information Advice and Support Services provided by LA (SEND Code of Practice (DfE & DoH), 2015) 2.17-19); Complaints procedure (SEND Code of Practice 11.67-11.111); Disagreement resolution service (DRS) (4 specific types of disagreement set out in SEND Code of Practice 11.8); Mediation service (SEND Code of Practice 11.13 – 11.38); SEND tribunal (Code of Practice 11.39-11.52)

The routes to resolving ASN disagreements in Scotland are as follows: Informal discussion at school and LA level; Mediation; Dispute resolution; ASND tribunal

the age of 16 may use the DRS, mediation and the SEND Tribunal. Other dispute resolution mechanisms are available to everyone with no age limits. In Scotland, parents, young people and children may use generic complaints procedures. In addition to parents and young people, children aged 12-15 with capacity are eligible to make a reference to the ASN Tribunal. Parents and young people, but not children, can request mediation, which was not included in the recent extension of rights because of mediators' beliefs that children would find the process too stressful and, in any case, disagreements were generally between parents and the school (Riddell et al., 2018).

There has been little research to date on children and young people's participation in mediation and tribunals and the available evidence is reviewed by Doyle (2019) and drawn on in the section below. (See M Doyle (2019), 'A Place at the Table: young people's participation in resolving disputes about special educational needs and disabilities', forthcoming, UK Administrative Justice Institute, available at www.ukaji.org). Small scale research by Soar et al. (2005) found that children's views were often presented to mediation meetings but they were rarely present. While practitioners were supportive in principle of children's participation in mediation, parents were worried about the stress which this might cause (Walsh, 2017). By way of contrast, in their response to the consultation on the 2016 legislation, Scottish mediators opposed the extension of the right to request mediation to children on the grounds that disputes requiring mediation generally involved parents and professionals, rather than children and young people (Riddell et al., 2018). Doyle (2018) suggests that mediation practice may reflect either a welfare approach, which involves weighing up a child's best interests, or a rights approach, informed by the belief that children and young people have an absolute right to be involved. She notes that data are not published on the nature and extent of children's participation in mediations or tribunal hearings, so it is impossible to know whether theoretical endorsement of participation is reflected in grassroots practice.

Cullen et al. (2017) were commissioned by the DfE and the Ministry of Justice to assess how well new and existing routes of redress were working for children, young people and their families. Although the research was meant to focus on children, young people and parents, the main focus appeared to be on parents. Key findings included the following:

- Person-centred EHC needs assessment and plan development were successful at fostering agreement and supporting the early resolution of any disagreements that did arise.
- Early and swift disagreement resolution were best for parents and for children and young people.
- Mediation reduced the likelihood of disagreements escalating to a Tribunal appeal and was cost-effective.
- Information, advice and support services differed in the quality and quality of information, advice and support offeree to parents, children and young people.
- Disagreement resolution services were generally not understood or used.
- The three main concerns expressed about SEND complaints processes were that the complaint might be ignored or not taken seriously, the response to the complaint might take too long to emerge, and the response might not help to put matters right.
- Few recommendations were made to health and social care about how they could help meet children and young people's needs.

It is evident that, even when new rights of redress are extended to children and young people, there are dangers that they will not be used. In 2003-04, the Children's Commissioner of Wales suggested that the children should be given the right to appeal to the Special Educational Needs Tribunal for Wales. The proposal was taken up by the Welsh Assembly Government and in April 2009, the Measure to extend children and young people's right of appeal to the Special Educational Needs Tribunal for Wales was introduced. The fundamental objective was to give parity of appeal rights to parents and their children. Research by Holtom et al. (2014) on the pilot project found that systems and processes for informing children and young people of their rights were well established and were regarded as working well. Support structures were in place to help children use their rights and professionals in the pilot authorities were enthusiastic about the enhancement of children's rights. However, a number of unresolved issues were noted including a lack of clarity about how disagreements between parents/carers and children would be resolved. In addition, it was not clear that children understood their rights to make disability discrimination claims. Most importantly, only one claim and no appeals were made during the course of the research, meaning that the impact of the extension of rights remained uncertain.

As noted by Doyle (2018), young people's legal capability is critical to their successful participation in dispute resolution. Commentators suggest that children and young people are often unaware of their rights and the legal processes associated with their enforcement (Parle, 2009). Pre-hearing advice and support are seen as essential (Drummond (2015; 2016a; 2016b), but such support services are thin on the ground and may be difficult to access.

Conclusion: Unresolved tensions and questions

In this final section, some outstanding issues and dilemmas are briefly reviewed.

Children and autonomy

There continue to be major debates about whether children should be regarded as autonomous actors with full rights of participation and redress. While some sociologists of childhood emphasise children's right to self-determination (Scott et al. 1998), most of those working in the field of children's rights suggest there is a need to recognise the ways in which children's autonomy differs from that of adults (Hollingsworth, 2013). Within the legal system, children are not considered to be fully autonomous rights holders, because childhood is regarded as a time for gathering and developing the assets necessary for full autonomy, protected by a category of 'foundational rights'. The notion of foundational rights is helpful, Hollingsworth argues, because it can be used to defend the need to treat children differently from adults. These practices include having a minimal age for criminal responsibility, differential sentencing for children and adults and a greater focus on restorative practices for children. These arguments are clearly relevant to the field of education, in terms of respecting children's autonomy while at the same time acknowledging its limits.

Individual and social rights

For both adults and children, there are debates on the relative emphasis which should be placed on social welfare rights and individual legal rights, indicating ongoing tensions between liberal/individual and social/collective understandings of rights and citizenship. According to Cockburn, before the advent of the welfare state, the rights agenda focused on 'the autonomous individual freely operating in the world without constraint' (Cockburn, 2013, p. 14). He maintained that liberal welfare states such as the UK tend to 'respect the autonomy of individuals contingent on their ability to be self-sufficient' (Cockburn, 2013, p. 14). This version of rights and citizenship, he suggests, tends to exclude children (and disabled children in particular) because it 'places children as an 'other' that is defined entirely as linked, dependent, reliant and constantly under the influences of other people ...' (Cockburn, 2013, p.14). Cockburn instead proposes that the link between rights and autonomy should be severed, with a focus instead on the notion of inter-dependence, reflecting the reality that at different points in the life cycle, and in different dimensions of life, people both give and receive care. Accordingly, the distinction between autonomous beings and dependent beings is artificial. While individuals need to exercise autonomy as far as they are able, there remains a strong role for the state in ensuring that adequate services are available to all.

Conceptual complexity in SEN/ASN policy and legislation

This review has highlighted the complexity in SEN/ASN policy and legislation, hindering the realisation of rights by children with SEN/ASN and their parents. Particularly in Scotland, parallel bodies of legislation draw on potentially competing principles of needs and rights, with a plethora of overlapping planning mechanisms. Across the UK, equality and education legislation are based on different conceptual underpinnings and offer parallel routes of redress. There are strong arguments for a radical overhaul and simplification of legislation in England and Scotland, particularly in light of the strong association between social deprivation and identification with SEN/ASN in both jurisdictions (Carmichael & Riddell, 2017).

The nature of children's participation

The review has also revealed the practical difficulties in operationalising children's rights in schools, classrooms and wider policy arena. Major problems persist in involving children in educational planning, particular younger children and those with the most significant difficulties. Tisdall (2008) suggests that 'the honeymoon is now over', and there is an urgent need to ensure that reality of participation in grassroots activities catches up with the rhetoric around the celebration of children's voices. Lundy (2018) notes that to date much participation has been tokenistic, and that this has been generally dismissed by children's rights advocates as fairly worthless. Revisiting these arguments, she concludes that 'tokenism is sometimes a start', and that not listening to children's voices is always wrong — 'a breach of their human rights'. Much of the literature discussed here has highlighted the problems and inadequacies in current attempts to facilitate children's participation. Nonetheless, there is a need for adults to engage seriously with views expressed by children. Lundy suggests that whenever attempts are made to seek children's views, this should be followed up by feedback which is child-friendly, fast and explains how the views

expressed will be translated into action. Efforts to capture children's voices which at first appear to be tokenistic may subsequently result in incremental social change.

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