



Autonomy, Rights and Children with Special Needs: A New Paradigm? Findings from an ESRC funded study

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Research aimed to investigate:



- The extent to which children (defined here as those of aged under 16) and young people (those aged 16-24 inclusive) with SEN/ASN are able to realise their participation rights effectively;
- The degree to which the autonomy rights of such children and young people intersect with those of parents/carers and are driven by, or influence, the decision-making of schools and local authorities;
- The way in which capacity for autonomous decision-making is understood and acted upon in different social contexts;
- The factors which promote or inhibit the realisation of autonomy rights by children and young people with SEN/ASN, including those who are looked after by the local authority;
- The impact of a children's rights-based approach on the broader education and social policy landscape.



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Research Methods



- Reviews of policy, legislation and statistics;
- Surveys of all local authorities in England and Scotland;
- Key informant interviews
- **Case studies of 36 children/young people and their families in six local authorities (18 case studies in each jurisdiction);**
- Each case study involved classroom observation and up to five interviews with child/young person, parent/carer & practitioners.
- Various elements of the research written up as Working Papers and Briefings available at: <https://www.ed.ac.uk/education/rke/centres-groups/creid/projects/autonomy-rights-sen-asn-children>



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Policy Background



Westminster and Holyrood Governments wish to ensure that principles of UN Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities are reflected in domestic legislation.

Education is principal universal service for children – therefore of major importance. Article 12 particularly relevant:

- 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.
- For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Also Article 7.3 CRPD's equivalent provision for those with disabilities but also calls for age-appropriate assistance for realisation of the right.



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Children with SEN/ASN in vanguard of extension of rights



Relevant legislation:

- Children and Families Act 2014 and SEND Regs 2014
- Education (Scotland) Act 2016, amending Education (Additional Support for Learning) (Scotland) Act 2004

Scottish Government claims that legislation goes further in advancing children's rights than English equivalent: **'It's the biggest extension of rights in Europe at the moment that we can evidence'**

Scottish Government interviewee



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New rights accorded to children (C) and young people (YP) with special educational needs in England (Children and Families Act 2014)



Right to ask local authority to:

- Carry out an assessment or reassessment of their needs (YP)
- Name a specific school in an EHCP (YP)
- Prepare a personal budget if there is an EHCP (YP)

Right to get information and advice or for information to be shared:

- Access to advice and information on SEND (C and YP)
- Info on right to give views to assessment (YP)
- Entitlement to copy of finalised EHCP (YP)
- Info on appeal and other redress rights (YP)
- Non-disclosure of EHCP without subject's consent save in some circumstances (C and YP)

Rights re having their views heard and considered:

- Their views, wishes and feelings (VWF) and the importance of their participation to be had regard to by local authority (C and YP)
- Tribunal to take account of VWF (C and YP)
- Consulted over local provision & local offer (C and YP)
- Input into decisions about assessment (YP)
- Comments on content of draft EHCP (YP)
- Inclusion of views in EHCP (C and YP)

Right to be involved in resolving disagreements and disputes:

- May select and participate in mediation (YP)
- Attend mediation (YP)
- Attend mediation, provided parent and mediator consent (C)
- Right to appeal (YP)
- Attendance at appeal hearing (C and YP)
- Access to disagreement resolution services (YP)



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New rights accorded to children (aged 12-15) with additional support needs in Scotland (subject to 'maturity and understanding' and wellbeing) post Education (Scotland) Act 2016



Right to ask local authority to:

- Find out if they have ASN
- Request a specific assessment
- Find out if they need a Co-ordinated Support Plan (CSP)
- Ask for a CSP to be reviewed

Right regarding information and advice:

- About their ASN
- Receive a copy of the CSP
- Be told about decisions about their rights
- Be asked if they are happy for information to be shared when they leave school

Rights regarding having their views heard and considered:

- Be involved in decisions about their support
- Access to support and advocacy to have their views heard (My Rights My Say)

Right to be involved in resolving disagreements and disputes:

- Ask for independent adjudication
- Make a reference to the first tier tribunal
- Be asked for their views during mediation

Not included: Mediation, placing requests



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Case study findings: Commonalities between England and Scotland



- Children had only a broad idea of the abstract concept of rights
- Children, parents and teachers generally believed that children's voices were heard in school – influence of UNICEF Rights Respecting Schools Programme
- Difficulties ensuring participation rights of children with complex needs.
- Children and parents from socially disadvantaged backgrounds more likely to feel ignored and disrespected.
- Support for children's rights in principle - However, teachers expressed reservations about allowing children autonomous rights & some believed children's rights had 'gone too far'.



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Children's knowledge and awareness of legal rights



They should have the right tae play. Have the right tae eat. Have the right tae get sleep. Tae clean theirselves. So like just imagine that I'm fourteen. I will, I think I'd be old enough to make a start, a wee bit making my own, no bad decisions. When I'm over sixteen I can make ma decisions cause I'll be a young adult. But, like ma wee cousin J., he's no auld enough tae make his own rights right now. So like just wait until he's older and then he can make his rights. (Lewis, 14 years, Scottish special unit, identified with SEBD/ADHD, SIMD1)



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Many children with SEN/ASN felt included – teachers facilitated participation and choice



Very nice teachers who like genuinely care about you. They care about your wellbeing and they always ask about how you are, how your holiday's been. Just actually show an interest. I'm in the DAS Department and I can say for any other people who have disabilities and who want to come here, it's very well organised up at the DAS. Yeah and like I say it's very nice and it's a very inclusive school. (Alan, 17 years, Scottish special unit, SIMD 2, diagnosis of ASD)

...we also try and include Holly in decision making and give her choices throughout the day. And the pupils have an input into the topics they want to learn so it's balancing their choice along with the curriculum expectations of what our balance for a broad general should be. So she has her own work tray and we try and filter in little things that are a personal interest to encourage her in other areas as well. So yeah I think, I think there's a really good balance. (Teacher of Holly, Scottish special unit, SIMD 3, diagnosis of ASD)



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But children from socially disadvantaged backgrounds expressed feelings of exclusion & alienation



I don't like the fact that I'm in a class with... two very autistic young people. And it gets a bit annoying. And I think I should be in a different class with the higher functioning people.

(Chloe, 14 years old, kinship care, Scottish special unit, identified with SEBD/ASD, SIMD 1)

I'm not allowed out for lunchtime... something happened in year four and I've not been out for lunchtime ever since that incident...I'm just really annoyed. It's not fair, because I've been doing this for eight months. (Lyron, 9 years old, English resourced provision, IMD 1, ASD.)



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Navigating SEN/ASN systems – contrasts between parents from more and less advantaged backgrounds



It was like fighting a losing battle. I was sick a' phoning them up and arguing wi' them and having meetings. And it just got me absolutely naewhere so I kinda just gave up. I thought, 'I'm wasting my time'. (Mother of Colin, Scottish special unit, SIMD 1, identified with SEBD,)

I got off to a good start with the primary school... I made myself heavily involved so that I could get access. So in that way I've sort of manipulated the system as well so I was sort of chair of the PTA for eight years and became a really key part of the school so then I had access to SENCOs just all the time, not in terms of, 'Oh can we have a meeting?' but I'd be at a Christmas Fair and the SENCO would be working with me and I'd be like 'Oh blah, blah, blah'. I did that on purpose so that I could sort of understand the school better and, you know, the teachers saw me differently because I was giving a lot back to the school so in a way I sort of manipulated the system as well. (Mother of Peter, 16 years, English mainstream secondary school, IMD 4, identified with Autistic Spectrum Disorder)



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In both jurisdictions, difficulty in extending choices to pupils with complex needs



You know, we're always looking at ways to give pupil voice, but a lot of it's on a level of [simple] choosing. So, you know, 'Do you want that for snack or do you want that for snack?' And then they can choose. (Catherine's teacher, Scottish special school)



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SL: *This is where the PFA [Preparing for Adulthood] is a very difficult document to work with when you're trying to say to students, 'What help do you need in the future?' ... They're like 'what's the future?'*

PV: *They can't understand the concept of tomorrow, let alone...*

SL: *Well their future is, I want to stay here 'cause this is the here and now, this is all they know. The thought of leaving something and not knowing, that's really difficult.*

PV: *That sets massive high anxiety levels for our students.*

(Pupil Voice Co-ordinator & Sixth Form Leader, English special school.)



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Lack of involvement of children/young people in dispute resolution



- None of the case study children/young people had been the party in a reference/appeal to the tribunal & none of the young people had requested formal mediation.
- Scottish school staff were generally unaware that children aged 12-15 could mount legal challenges.
- Concerns that right to access the tribunal in Scotland might be abused.



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Teachers' doubts about children's rights of redress in Scotland



I think [the changes] took me and I think most a' my colleagues aback. I don't think any of us as head teachers ... knew that it was coming. It may well be that some youngsters live in environments where they don't have parents and it's carers who don't maybe care the way they should or they're in an institution. Or simply their parents are, you know, not capable or able to do it for them. I suspect there's a whole raft of areas out there where this might seem to be a good idea, it might be applicable. But I think for the mainstream environment ... we're not so sure. (Head teacher, Scottish mainstream secondary)

Carl for example ... he has autism and he's quite literal about many things ... So many times in the past he has accused staff of mistreating him in his old school and so on which might be fair to an extent, I don't know, I cannot tell. However, I can see if it's not true and if Carl would be able to take that to court, I think it would be a very big case and an unjust case in a way, if it's not true to be honest. (Scottish learning support teacher)



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Parents often took the lead in deciding which school placement in child's best interests



- The consent of the child or young person was sought when possible to ensure their acceptance and co-operation.
- Children accepted that parents might make decisions on their behalf.
- As they got older, young people became more involved in educational decisions along with their parents.



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Parents, children and school choice



I'd had a pretty tough time in my old school. I wasn't getting the right education. I didn't get the education that I needed. And ... they just gave me a lot a' free time so my parents asked me if I'd like it here. And obviously at first I wasn't really keen but then as time went on ... I got more used to it. (Laurie, 14 years, Scottish residential special school, SIMD 1, identified with ASD)

He did have a say and we did try to discuss and advise and that kind of thing, yes...we did try to come to the best decision as possible as a family and then also in discussions a bit with his teacher and stuff. (Father of Kei, 17years, IMD 5, FE College, identified with moderate learning difficulties)



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Major differences between England and Scotland – children's involvement in educational planning



- Statutory support plans (CSPs) rarely used in Scottish schools – held by only 0.3% of the total school population. Since 2004, year on year decline.
- In England, EHCPs held by just under 3% of pupils – and numbers are increasing.
- In Scotland, only 2 out of 18 case study children had CSPs, c.f. 14 out of 18 in England with EHCPs.
- In Scotland, most parents do not know what type of plan their child has and children are not routinely involved in formal educational planning.
- In England, requirement for child's participation in drawing up & reviewing EHCPs increased degree of participation.



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Access to statutory support plans: Scottish parents' experiences



I think there needs to be more information to parents about a CSP cause we had to kinda google what a CSP meant and what it was, cause the school never gave us any, really, in-depth information about a CSP. And then if there was any appeals, disagreements with the CSP we were never told any procedures how we would go about that if it got to the stage that things weren't happening which obviously happened with us. And then I just feel that the schools need to be more aware as well of what a CSP actually is. (Mother of Tom, 14 years, Scottish mainstream school, SIMD 3, identified with physical disabilities)



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In both jurisdictions, children might opt out or be deterred from participating



I guess that, this comes down to the child's capacity actually. Certainly at primary, whenever we had child planning meetings, David would complete the My Views sheet with the help of the Support for Learning teacher but he is not keen to be involved in meetings. And I personally don't think he would have gained much from being involved in something he didn't want to be involved in. And whenever we have a meeting in school I always give him the option to come. And he's quite adamant he doesn't want to come which is him executing his right, I suppose (Mother of David, 13 years, special unit, SIMD5, identified with physical and learning disabilities)

I don't know whether I'll take Carol because, you know, like Carol can talk. We could have a review that will last all afternoon if I took Carol in, so I'll sit them down and talk to them about it and I think as they get older, then they do [participate]. (English special school class teacher, regarding Carol, 8 years old, IMD 5, identified with Autistic Spectrum Disorder)



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Conclusions



- In both jurisdictions, broad support for children’s rights of participation – but difficulties in ensuring participatory rights of children with complex needs.
- Parents continue to act as children’s principal advocates – middle class parents mobilise social, cultural and economic capital to navigate the system.
- In Scotland, children have greater rights than English counterparts - but little knowledge of the new legislation in school – LAs have done little to raise awareness.
- Doubts about viability of children’s autonomous rights and fears of abuse.
- Lack of statutory support plans in Scotland jeopardises children’s rights – level of child participation in educational planning greater in England.