



KIDS Manifesto for Change

KIDS has over 50 years on the ground experience working alongside disabled children, young people and their families, providing support, advice and information from birth to 25, whatever their disability.

Our ambition is for every disabled child or young person to meet their own potential. We believe that the right support and a range of opportunities need to be in place to ensure that every individual can thrive.

This means that learning, play and social opportunities are available from the early years through to adulthood, supporting disabled children and young people's development and wellbeing. It means families aren't having to fight to get the help their children need and it means the views of disabled children and young people are at the heart of all decisions made about them – at individual, service and policy levels.

To make this a reality and transform the lives of disabled children and young people, we have identified five clear areas of action where Government action is needed.

1. Getting it right in the early years

There is vast evidence that confirms that what happens in the early years of a child's life lays the foundation for their future health, wellbeing, learning and earnings potential. Research shows that good quality pre-school education can result in children at age 5 having better language skills, a better conception of numbers as well as improved social and behavioural skills.ⁱ There is also evidence that early years' childcare settings have an important role to play in a child's physical development.ⁱⁱ Given that children with special educational needs or a disability (SEND) will need additional support to help them in their development in one or more of these areas, it is even more important that they can access quality early years education and support – from formal nursery provision to home learning to social and play opportunities.

When the right support is in place, we know that it can make a significant difference. For example, we've seen disabled children accessing the right therapies and help in our nurseries that have resulted in them going on to a mainstream primary, when it had previously been predicted that they would need a special school place. Last year, 7 of the 17 children in our Basingstoke nursery whose destination on leaving had been predicted as a special school, instead went into mainstream. Replicating this type of outcome across the country would not only ensure improvements for individual children but could also result in significant savings to the public purse, avoiding the need for more costly and complex support.

However, there is a significant shortfall in adequate early years provision for children with SEND. Just 21% of local authorities report that there are sufficient childcare places for disabled children in their area, meaning most local authorities are failing in their duties under

the Childcare Act 2006 to ensure provision is in place. ⁱⁱⁱ As a result, families are unable to take up the Government funded childcare¹ that they are entitled to and some of the very children who would benefit most from an early years' education are not able to access it.

A lack of national leadership on early years as whole and support for early years for children with SEND in particular means lies at the heart of the insufficiency of the right help in the early years for disabled children. The recently published SEND and Alternative Provision (AP) Improvement Plan is welcome in its recognition of the importance of early years. There also appears to be a clear intention to include early years in some of its key reforms. To make that intention a reality, the Department for Education (DfE) must involve those with expertise in SEND in early years, as implementation of the plan progresses, ensure early years is central to the new 'SEND National Standards'², as well as in the Local Inclusion Plans that will be developed in each local authority area.

The lack of national attention to early years shows through in the dearth of data routinely collected and published about the needs of children with SEND in early years and the provision available. This means that there is not a clear picture nationally of what is currently happening and what needs to change. It also means that at local level, councils are not properly planning for the needs of their local population. This is reflected in the insufficient provision of formal nursery placements as outlined above, but also in the lack of availability of inclusive and specialist play groups and social opportunities, as well as shortfalls in the provision of Portage Home Learning (more below).

There are also significant issues in how funding works for early years SEND. There are a number of funding pots that should be available to nurseries from central Government and the local authority to support children with SEND in their settings. Funding is needed so that settings have access to any specialist equipment as well as the right number of properly trained staff. In a survey of providers by the Early Years Learning Alliance , 87% said the funds that they were provided with were insufficient. Moreover, nurseries often aren't able to apply for additional funding until the child has started with them, presenting a significant risk for the provider, as one explained in the Early Years Learning Alliance research:

“It's not really the delay in receiving the money that causes the issues ...it is more the lack of information on whether or not the panel have decided to honour our application or at what rate until well into the term that it is needed. How do we know whether we can afford to take on additional support staff for those with significant needs or not?”

Improving the knowledge and understanding of different SEND among all early years educators would also help make all settings more inclusive and make it easier for settings to support those with SEND. We welcome the review of the Early Years Educator (EYE) Level 3

¹ In England, all three- and four-year-olds are entitled to what is commonly called “15 hours of free childcare”, which amounts to 570 hours per year. Some children, including those with an Education, Health and Care Plan (EHCP) or who receive Disability Living Allowance are entitled to their 570 hours of free childcare from the term after they turn 2. In addition, children aged 3 of working parents with an income up to £100,000 may also be entitled to an additional 570 hours child care per week.

² The development of new National Standards on SEND is a key mechanism in the SENDAP Improvement Plan for securing the ambitions for the system the Government wants to see. These National Standards will set out ‘clear and ambitious expectations for what good looks like in identifying and meeting a range of needs’ in every area of the country and services will be expected to meet them.

criteria, looking at the inclusion of SEND as a standalone criterion and hope to see changes made. We also support ongoing funded DfE programmes, such as the Early Years SEND partnership to support the ongoing delivery of training in SEND for early years staff.

Early years educators supporting young children with SEND tell us they are also struggling to access wider support from local health and social care services for the children in their care. In our experience, this has become even more acute since the pandemic, which has increased demand. Workforce planning for SEND specialists across health and care, committed to in the SENDAP Improvement Plan, needs to look at the specific needs of children under 5. If they can get this support early, their needs can be reduced in the long run.

Portage Home Based Learning

Portage is an invaluable service that involves early years educators going into the home to provide support to help a child's individual development needs. As well as ensuring better planning for its provision, we propose that a flexible use of the 'free' childcare entitlements may help increase access to Portage for those who would benefit from it. In the short term, this could include children who would benefit from input from an early years educator, while their families secure a childminder or nursery placement.

Recommendations:

- The Department for Education (DfE) should consult those with expertise in early years and SEND as they develop the new 'National Standards' for SEND provision, the new guidance for local SEND Partnerships and guidance on the content of Local Inclusion Plans that will be developed as a result of the Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan.
- DfE should reform the way the funding for SEND in the early years works, to ensure it is sufficient, allocated consistently across England and to make sure it is available before a child starts at a setting, allowing sufficient time for planning and recruitment.
- DfE should review their data collections through the Early Years Census and ensure data on early years is included in the new local and national inclusion dashboard to ensure there is a clear picture, nationally and locally of the education, play and social provision children with SEND are accessing in the early years and any gaps.
- Local authorities should use this data to inform local planning, including the new Local Inclusion Plans, Health and Wellbeing Plans and the Local Offer to ensure there are sufficient childcare places for children with SEND, sufficient Portage and adequate supply of local inclusive and/or specialist playgroups and activities for children with SEND under 5.
- DfE should update the Early Years Educator (EYE) Level 3 criteria, to include SEND as a standalone criterion and continue to invest in programmes to improve the knowledge and expertise of early years educators in SEND.
- Joint action from the Department of Health and Social Care (DHSC) and DfE on workforce planning for specialist staff (e.g. speech and language therapists) should include planning for support that children with SEND in the early years need from these specialists
- DfE should develop a pilot to look at how the 15-hour and 30-hour childcare funding could be used flexibly to pay for Portage Home Based Learning.

2. Navigating a complex and adversarial system

The adversarial and complex nature of the system for accessing support for disabled children and young people is well documented. Families first struggle to get their child's needs identified and frequently face long waiting lists for diagnosis. Then from the moment a child receives a diagnosis, they and their family are plunged into a complex and often frustrating system where getting the right support can feel like an almost impossible task.

Research by numerous disability organisations outlines how parents commonly talk about accessing help for their disabled son or daughter in the language of the battlefield. They talk about having to 'fight' for the right help.^{iv} The recently published SENDAP Improvement Plan, acknowledged that there was a lack of parental confidence in the system as a result of its adversarial nature and long delays for support.^v

To help parents navigate the system and get the right help for their child, KIDS are piloting a SEND Navigator service in Birmingham. The SEND Navigators we employ work in partnership with the family to build a personalised support plan, before providing practical and emotional support. The Navigators connect families with local services and work to help the family access the right provision and support. In our experience, a lack of understanding of rights and entitlements, as well as a lack of knowledge about what is or could be available locally (using the right funding pots) stops disabled children, young people and their families from accessing the support they need. The Navigator can fill this gap.

Our current pilot is for families with children in early years and we are already seeing an impact. Universally, parents who use the service report feeling less isolated and we are securing outcomes and provision for them that otherwise wouldn't have been available. For example, we worked with one parent to get the help her child needed at one nursery only for that nursery to realise it couldn't meet the child's needs. We were able to get the funding 'frozen' while we helped find a new setting, which was eventually secured. The Navigator service was particularly invaluable with knowing how to get the funding 'frozen', so that it could be redeployed to the new setting enabling the child to start nursery in a timely way. In addition, parents tell us the Navigator service is impacting positively on mental health, with one parent saying they felt they did not need to see the GP thanks to the support. Given nearly three quarters of children with a mental health condition also have a physical condition or development problem, the SEND Navigator Service can support mental health and wellbeing in children who are particularly in need^{vi}.

While our current pilot is for early years, we see the service expanding to work with families of disabled children and disabled young people themselves across all ages. The SEND Navigator Service can be delivered at relatively low cost, but our experience to date suggests we can achieve significant benefits to the families we support. We understand there are similar services being provided elsewhere.

Recommendation:

- DfE should commission a feasibility study to capture existing practices that achieve the objectives of the KIDS SEND Navigator pilot and assess the viability of providing a Navigator for every family with a disabled child and to young disabled people too, as needed.

3. Making community provision and care and support work for disabled children

Attending after-school clubs, and holiday clubs, as well as participating in local sporting activities or other hobbies is vital for disabled children in helping them to make friends – with disabled and non-disabled peers - in supporting their development by exposing them to new experiences and in promoting wellbeing. It can also help support them to access and stay in formal education.

We believe that disabled children should be able to access activities in the community in the same way as other children, with the local authority and local providers either ensuring that activities that are available are inclusive or developing specialist activities as appropriate. As with early years, key steps need to be taken by local authorities so that needs are identified and included in local planning to secure provision. Local authorities also need to ensure they are consulting with disabled children and their families as part of this.

When it comes to more ‘formal’ entitlements for support, under the Children Act 1989, disabled children are children in need. This should mean they have their needs assessed by the local authority and care plans developed as a result. In practice, funding cuts combined with a confusing patchwork of legal duties across a number of different bits of legislation - meaning that rights and entitlements are not as clear as they seem at first glance – has resulted in disabled children and their families struggling to access the support from social care they need.

As part of the Disabled Children’s Partnership (DCP), we have welcomed the announcement that there will be a review of social care legislation as it applies to disabled children to make sure rights and entitlements are clear. However, we also need to see significant investment in health and care services for disabled children to fill gaps in services and secure improved outcomes.

Recommendations:

- DfE should ensure that access to community provision – after school clubs, holiday clubs and other activities should form part of the new National Standards on SEND provision, as well as in the guidance on the content of Local Inclusion Plans that will be developed as a result of the SENDAP Improvement Plan.
- Local authorities should consult with disabled children and their families as they develop their new Local Inclusion Plans and as they revise their Local Offer to ensure that they are planning to meet local needs for community provision.
- DfE and DHSC should invest £2.1 billion in health and social care for disabled children to fill the gaps in service provision^{vii}
- DfE and DHSC should establish an ‘Early Intervention and Family Resilience Innovation Fund’ to support projects that transform disabled children’s health and social care by fixing problems at the earliest point of identified need and by focusing on the family as a whole, with a view for these projects to be rolled out more widely, based on evidence that they work^{viii}.

4. Getting the right help into adulthood

As they move into their late teens and early twenties, disabled young people tell us they want to be able to access suitable education, training, employment opportunities, as well as extra-curricular activities and support that will support them to thrive in adulthood. All too often however, they are held back by service silos and poor transition planning, a lack of planning

and investment in post-16 and post-18 education and support and a lack of inclusive or accessible youth services and activities.

Service silos and transition planning

Disabled children receive services and support from a range of public services – health, care and community services and education. As they get older, they will no longer be eligible for support from the same services. Some types of support may also not be available from adult services and eligibility criteria in adult services is typically more restrictive. Many families describe moving out of children's services as like 'falling off a cliff', as suddenly the support they had available to them before disappears. To ensure a smoother transition, it is vital that planning for adulthood for a disabled child starts as early as possible and involves children's and adult services working together so that as far as possible the right help can be put in place from the start of a young person's transition into adult services. Moreover, the needs that are identified through these plans need to inform service planning for adult services. We welcome the commitment in the SENDAP Improvement Plan for new guidance on transition to start to address these issues.

It is also vital that the support that a child or young person might need to be more independent in adulthood is built into a child's Education, Health and Care Plan, as they grow older. This might mean for example, schools or local authorities ensuring the provision of travel training or workshops about managing finances, wellbeing or self-care.

Schools and local authorities should also look to commission and promote these types of support more widely to all children with SEND, to make sure they are available if needed, regardless of whether they are included in an EHCP. To support this, the new SEND National Standards and the new Local Inclusion Plans being developed as a result of the SENDAP Improvement Plan should include these types of services.

Post-16 and post-18 education, training, and employment opportunities

The 2014 SEND reforms in theory expanded provision for children with SEND up to 25. In reality, the changes were not accompanied by a clear national plan with to develop provision and support for 16-25s. Given the longstanding reductions in investment in Further Education (FE), it has been a challenge for post-16 and post-18 providers to ensure adequate provision for young people with SEND. Meanwhile, while, there have been some welcome Government investment and focus on supported internships and in ensuring that apprenticeships are accessible for disabled young people, young disabled people we talk to are unclear about what options are and how they can access them.

Making a young person's SEND Navigator Service available to all young disabled people would be invaluable in helping them understand the various education, employment and training options available to them, Such a service should also help ensure that for those with the most complex needs the right education and support for opportunities that help them meet their potential are properly included in EHCPs.

The SENDAP Improvement Plan identifies transition as a priority, but there is little detail on how the Government will ensure sufficient post-16 and post-18 provision. As implementation progresses, we expect to see quality provision of education, training and employment support for 16-25s to be included in the new SEND National Standards, as well as in Local Inclusion plans, supported by commitments to funding and a new 16-25 strategy to help secure delivery.

Youth services and activities

The Government recently published the results of its review of youth services, which has informed its new Youth Guarantee. As part of the review, they heard from around 6,000 young people across the country. Collectively, they asked for priority to be given to three areas; regular clubs and activities, adventures away from home and volunteering opportunities.

When we talk to young disabled people, they tell us they also want these opportunities so that they can socialise and meet new people, take part in interesting experiences and to develop their skills. We therefore welcome the move by Government as part of its new Youth Guarantee to focus part of its funding to increase volunteering on making sure opportunities are accessible to young disabled people. However, we would like to see further action to ensure that its wider offer provides both inclusive provision, so that young disabled people can take part in youth activities alongside their non-disabled peers and specialist provision and activities are also developed for those disabled young people that would benefit.

Recommendations:

- Local authorities and schools must ensure that they identify needs for independent living skills, e.g travel training, support to develop self care skills, as part of a young person's EHCP and ensure support is in place to meet that need
- DfE should ensure that independent living skills are included in the new SEND National Standards as well as in the guidance on what should be included in Local Inclusion Plans, so that these services are planned for and commissioned locally
- DfE should commission a feasibility study to capture existing practices that achieve the objectives of the KIDS SEND Navigator pilot and assess the viability of providing a Navigator for every young disabled person
- DfE should ensure quality provision of education, training and employment support for 16-25s is included in the new SEND National Standards, as well as in guidance on what should be included in the Local Inclusion Plans
- DfE should develop a new strategy on 16-25 SEND provision, backed by funding to make sure that needs and ambitions of this age group are being properly identified, supported, planned for and met.
- The Department of Culture, Media and Sport (DCMS) should work with uniformed youth organisations and other national organisations, like the Duke of Edinburgh and the NCS, to make sure their offer is inclusive and is informed by consultation with disabled young people and through developing links with disability organisations.
- DCMS and National Youth Agency should ensure that work on workforce development includes improving knowledge and expertise in the youth sector on disability and how to support disabled young people
- Local authorities should consult with disabled young people in their area on their provision of youth services and on the Local Offer and ensure there are a range of available inclusive universal services and specialist provision that meet the need identified through the consultations.

5. Let us shape the decisions that affect us

Disabled children and young people need to be at the heart of decisions made about them, whether that's at an individual level, service level or strategic/policy level. They are the ones that understand their needs the best and they have the right to shape the decisions that affect

them. The SEND Code of Practice sets out clear duties on local authorities both to involve children and young people in decisions over their own individual support and also in reviewing local educational and training provision and social care provision and in preparing and reviewing the Local Offer.

KIDS are pleased to be working with the Council for Disabled Children (CDC) to deliver *Making Participation Work*, funded by DfE to build capacity at national and local level to ensure the participation of young disabled people. We know some areas are already doing well on this, ensuring consultation on local plans, involving young disabled people on steering groups or in delivering disability awareness training. However, every local authority needs to ensure that participation of young disabled people in local decisions that affect them becomes routine. We are keen to support them to do this, through developing resources and sharing practice.

Our work to deliver *Making Participation Work* includes supporting DfE to involve young people in the development of SEND policy at a national level. However, we believe that the principle of involving disabled young people should also be part of wider decision-making within the Department and across Government. Notably, as part of its Youth Guarantee the Department for Culture, Media and Sport is continuing to support youth voice activities to ensure young people's views are captured and heard across Whitehall. The views of disabled young people must be included in this work.

Recommendations:

- DfE and local authorities should work together to ensure all local areas can demonstrate how they are involving disabled young people in local decision making on SEND services and support
- DfE should ensure that participation of young disabled people is included in the guidance to local SEND partnerships on who needs to be part of the partnership and what the new Local Inclusion Plans should include.
- Local authorities should make use of the resources and support KIDS and CDC develop through *Making Participation Work* and ensure they are involving disabled children and young people in decision making on local provision that affects them.
- DCMS should ensure that disabled young people are properly represented in their youth voice activities to ensure youth engagement in policy development across Whitehall.

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ⁱ <https://discovery.ucl.ac.uk/id/eprint/10005309/>

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1001610/IELS_Physical_Development_Report.pdf

ⁱⁱⁱ <https://www.coram.org.uk/resource/coram-family-and-childcare-survey-2022>

^{iv} See for example: https://s2.chorus-mk.thirdlight.com/file/24/OHTGORW0HHJnx_c0HLZm0HWvpWc/NAS-Education-Report-2021-A4%20%281%29.pdf

^v

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1139561/SEND_and_alternative_provision_improvement_plan.pdf

^{vi} <https://www.local.gov.uk/about/campaigns/bright-futures/bright-futures-camhs/child-and-adolescent-mental-health-and>

^{vii} <https://disabledchildrenspartnership.org.uk/the-gap-widens/>

^{viii} <https://disabledchildrenspartnership.org.uk/we-need-a-disabled-childrens-innovation-fund-heres-why/>