

## Joint Treasury & DfES Policy Review of children and young people

Contact details for respondent	
Name	
Job title	National Development Director, Kids
Do you represent an organisation?  (if so, name of organisation and type: e.g. voluntary, public body, private company).	<p>Kids. A national charity established in 1970. Kids was based on the concept of "parent partnership", with its founder aiming to support parents whom he recognised (as did a speaker at the last Parliamentary Hearing) as "the world expert" on their child. Today Kids operates in five English regions, providing an unusually wide range of services for Disabled children, young people and their families. Kids also works extensively to support the inclusion of more Disabled young people in the mainstream children's sector, where it is known as the leading organisation for inclusive play and childcare.</p> <p>Kids was a pioneering organisation in providing Portage in England, and still delivers extensive early development support, working with 27 Sure Start programmes in 2005/6. Kids was a pathfinder organisation under the Early Years Support Pilot Programme, and continues to work with the DfES to roll out this training. Kids runs specialist and inclusive play and childcare provision, and promotes the inclusion of Disabled children in play and childcare nationally under a strategic contract/grant from the DfES. Kids is also working with groups of Disabled young people in each of its 5 regions to develop guidance for inclusive leisure and youth services.</p>
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	Which area of the review are you responding to? (please mark X)
Prevention strand	
Review of Disabled children	<b>X</b>
Strategy for youth services	<b>X</b>
Review of high cost, high harm families	

## **Review of Disabled Children**

### Objective:

**To improve outcomes and life chances of Disabled children through the development of effective and accessible services for Disabled children and their families**

### ***General Issues (relating to the scope of the review):***

#### ***A. Services specifically for Disabled children, including how specialist services for Disabled children support access to universal services, specialist services provided in a universal setting and how universal services refer children to specialist services***

Under the current Disability Discrimination legislation, universal services for children and young people need to include Disabled children and offer them services equal to those for non-Disabled children. Good services which children enjoy, could best be achieved by supporting universal services to develop as inclusive settings (i.e. an approach that embraces difference generally) alongside a child centred approach, which would involve specialist support being brought as required. Thus, support would be offered from trained specialists, for example, in the areas of speech, language and communication. This would promote social inclusion as well as lay the foundations for independent living later in life for Disabled young people.

Kids offers a wide range of services to support Disabled children and their families, such as adventure playgrounds, nurseries, respite care, parental support and Portage. The services offer a full choice and specific support that help make the lives of Disabled children and their families easier whilst including them in society. We also provide 'reverse inclusion' services that are predominantly specialist, but include non Disabled children in the scheme as well. A key factor in these services is often the high staff: child ratio.

The voluntary sector holds a wealth of experience in this field, which it would be invaluable to build upon. We would like to see a programme to support voluntary organisations in developing new and innovative services – that go beyond the current, sometimes limited, expectations of local authorities – something that is extremely difficult in today's restricted "contract culture".

#### ***B. Childcare services, which are of particular importance in the early years for children's development and to support their parents***

Since the introduction of the Ten Year Strategy for Childcare and the Childcare Act, there has been more emphasis on providing high quality, affordable childcare for Disabled children. However, parents of Disabled children often have very limited access to appropriate and affordable childcare (see latest research "On Holiday!" from the Thomas Coram Research Unit at the Institute of Education, commissioned by the DfES but as yet unpublished). Kids work with universal services, through the DfES funded Playwork Inclusion Project, has demonstrated that an approach which concentrates on creating a wholistic "inclusive setting" is most successful in including Disabled children, rather than the traditional approach of funding simply following the individual child. Part of that "inclusive setting" approach does, though, involve bringing in individual support workers when and where needed (as opposed to the traditional "one to one" worker for every child with "x" specific diagnosis). Ofsted's 2004 research on settings achieving a Good standard for inclusion concurred with this – and the importance of a positive attitude among staff.

The Institute of Education research revealed, however, that contrary to the Childcare Strategy, health professionals providing additional services for Disabled children do not expect their parents to be employed, or certainly not in full time employment. Instead, parents are expected to attend case conferences, reviews speech therapy sessions, etc during usual working hours – to an extent that would jeopardize any job they may take.

School holidays are particularly stressful times for families with Disabled children. Summer schemes are welcomed and seen as essential, but places are usually rationed – and often only allocated at the very last minute: again militating against full time employment for parents. The lack of structure during holidays is particularly difficult for children with autism and their families. Parents are reported as wanting more outdoor and energetic holiday activities for their children. In addition to a lack of holiday provision, other support structures, such as speech and physio – therapists are often not available during holiday periods.

The Playwork Inclusion Project has established and facilitates Regional Inclusive Play and Childcare Networks in each of the nine English regions. Members meet on a termly basis not only to share good practice and network, but to discuss and develop practice around positive support mechanisms for inclusive childcare. The results of this include a “Checklist for Inclusion” for practitioners (used both to introduce early years settings to inclusive practice and as a quality assessment tool); the Kids Framework for Inclusion for Local Authorities – outlining 12 key factors for creating successful inclusive services; and a growing number of short briefing guides on specific inclusion supports – the latest being an examination of the value of a “bridging” individual or organisation to link Disabled children, their families and the play/childcare setting. These documents can be downloaded from: [www.kids.org.uk/NDD/publications](http://www.kids.org.uk/NDD/publications).

Kids has also found that parents often want to look after their children full time, and therefore are unable to work. This creates an additional problem of poverty, and families with Disabled children are more likely to need extra resources and information whilst being on a lower income. Some of these parents would prefer to care for their own children and be paid to do it.

One recommendation that Kids offers is that parents be trained to be carers, so that when they qualify they can be paid to do this as a full time job – whether for their own or other children. This would also solve the issue of employers having to let employees who are parents of Disabled children take time off work to meet with professionals working with their children.

It is as yet unclear whether or to what extent, the new Extended Schools initiative will benefit Disabled children – although of course in they must be able to access and use the services. (In addition, the Disability Equality Duty will require schools to publish a Scheme that covers all extended activities they provide, which will highlight areas and schools that need to become more inclusive and representative.) The extended schools programme is already open to special schools, and it appears that many are participating. We acknowledge and appreciate all work that is being done in this field, including the research work between The Council for Disabled Children and the DfES, however, changes could be made to further include special schools. For example, to further the extended schools programme, we suggest that a pilot could be implemented with special schools that welcome non Disabled children into the world of Disabled children for their mutual benefit (a process that has been termed “reverse inclusion” by the Institute of Education). This could be done in partnership with a specialist service delivery, voluntary organisation such as Kids.

However, in mainstream Extended Schools become primarily homework or very specific activity clubs, an opportunity for the wider inclusion of Disabled children will have been lost – and they will risk simply continuing to have the label of SEN attached to them, and be related to separately. In our experience, free play offers one of the best opportunities for Disabled and non Disabled children to get to know each other and make friends, yet play has been excluded from the “core offer”. As active members of the Children’s Play Council we join them in calling for that to be changed, and for play spaces and facilities that are accessible, welcoming and engaging for all children.

From our work with universal services, Kids strongly recommends that all training for play and childcare workers should include disability awareness/equality and inclusive play. Towards this end, we have worked for several years with SkillsActive, the Playwork Sector Skills Council to achieve inclusive playwork National Occupational Standards, and recommend that the Children’s Workforce Development Council standards adopt a similar approach to inclusive practice (rather than stand alone SEN standards).

### ***C. Appropriate support for Disabled children during the school years and in making the transition into adulthood***

Transition is a key area that needs to be developed with regard to policy and services offered. For many Disabled children and young people, change is particularly demanding and difficult and they therefore need additional support during times of transition. Many of these can be predicted and planned for, such as starting at a nursery, moving to a primary school, moving to a secondary school, leaving formal education, leaving home. Others changes cannot be planned for – the unexpected illness or death of a close relative, for example. We believe that transitions become less traumatic with the increasing support from inclusive educational and out of school services, which are becoming more widely available. Although Early Years settings provide extra support in transitional periods, for example through the appointment of a SENCO who will make links with other schools, Kids believes that more services need to be provided urgently for transitions post-16 years, particularly for young people with more complex requirements.

Kids is concerned that, with the merger of Local Authorities Children’s Social Services and Education, the transition to adult services – already experienced as the most traumatic transition – could become considerably more difficult as inevitably the links between Children’s Social Services and Adult Social Services will become weaker. This emphasises the need for a developed multi-agency approach; this is already established in the SEN Code of Practice, however, Kids is concerned that without an established department, these processes may take too long, by which time the Disabled young person has lost out on key development time.

In addition, Kids believes there is a need for more services which emphasise developing independence and inclusion skills, improving their self confidence, as the transition period approaches (for example, encouraging Disabled young people to take public transport rather than relying on parents or taxis). At the moment, we are concerned that many services received by Disabled teenagers do not actively prepare them and their families for more independent living in their late teens and 20s. These wider and more creative services should relate appropriately to a young person’s biological age, irrespective of individual diagnoses.

A key sample of evidence relating to transitional services for young people is Kids’ recently established Young People’s Inclusion Project (YP-in). The project works nationally with young people aged 11-19 years old who have a wide range of

impairments, who research and assess current leisure and youth services provision. Towards the end of this 3-year programme, the young people will produce national guidance on inclusive leisure. Young people, regardless of impairments, are still teenagers and want to have their own lives separate from their parents, who by this time are predominantly thought of as the young person's primary carers. Therefore development is offered within the context of being teenagers, and doing what they want to do. If more projects could be funded like this, then the type of service could expand to offer more advice and support for Disabled teenagers to get a job, complete training, and improve particular skills. Further details of the YPin project are available at: <http://www.ypin.net>.

Kids also offer a 'befriending' service, which operates in Bristol, London and Yorkshire & Humber. The scheme helps young people to take part in social, leisure or sporting activities by providing a trained volunteer or worker to accompany them. This aids the transition process, as Disabled young people are given more freedom and independence to carry out activities that are common and frequent to their non-Disabled peers.

***D. How expenditure by one service/department can avoid or reduce concurrent or later expenditure by another department.***

There needs to be more consultation between different departments and organisations to avoid duplication of work, and making sure that Disabled children and their families' needs are met. In particular, early assessment by one department could save another department work and funding in the future. Kids is particularly concerned that the Early Years Programme developed through the DfES, has not received appropriate funding to embed it in early years services nationally. Such support could be crucial in assisting Disabled children to become more independent, which could release the reliance on benefits.

Good services exist for Disabled children and their families. However, due to inadequate funds, local authorities are increasingly contracting out services to large commercial organisations: Kids would question the specialist expertise and knowledge base of staff in many such organisations. By using different smaller organisations, we believe a better service would be provided. Expenditure could be saved in the longer term if measures are taken to help release the expertise and "added value" that voluntary organisations can bring to providing services for Disabled children.

Additionally, the wider availability of more focused support and development services – such as those provided by speech and language therapists, music therapists (especially for children with ADHD and autism), art therapists and play therapists, could result in a lessening demand on services and support as children grew older.

Kids would also like to see research into delivering services according to a rights-based social model of disability approach, as we understand this to be more conducive to discouraging a lifelong dependence on care services. Services based on the social model it would differentiate between the focused support required by a child with a particular impairment, and the general care assistance required to overcome external disabling barriers, for example inaccessible buildings or transport, and unhelpful attitudes.

Finally, as one of the pioneers of Portage, Kids would like to see this a hugely successful early learning and development service being offered in all local authorities across the UK.

## **Key questions:**

### **1. The changing profile of Disabled children, for example, due to increases in complex disability and rise in Autistic Spectrum Disorders, profound and multiple learning disabilities and low birth-weight babies and the challenges this poses to services.**

The increase in the numbers of children with autistic spectrum disorders and ADHD has been evident to us for many years. For example, our adventure playgrounds – which offer the opportunity for active, adventurous play and risk taking in safe, enclosed spaces - identified a prevalence of children with these conditions in the late 1990s.

We are greatly concerned at the lack of free play opportunities for all children in school, but particularly for Disabled children, and would cite the articles and new campaign launched in recent days to counter the lack of activity and play in children's lives. We would refer to the growing wealth of evidence in favour of play, especially research by the Children's Play Council, and the positive effects of play on the social and emotional development of children.

With regards to education services, although resources appear to be increasingly in place for children with complex requirements, there is not enough provision for children with Autistic Spectrum Disorders and we believe that many mainstream schools do not cater well for children with specific learning difficulties. Children learn different skills at different times, therefore education services need to adapt to account for children with different impairments.

### **2. What progress has already been made in addressing the needs of Disabled children and their families?**

Kids is a charity that focuses upon providing services that address the needs of Disabled children and their families. It offers resources for 'under 5s', such as home visit, Portage, inclusive nurseries, and parent and baby groups. These provide support, information and allow children to develop social and developmental skills. We work in Sure Start projects to provide services, and language and interaction groups to support children with communication difficulties. Kids operates from an 'inclusive' perspective, helping young children take part in community activities, as well operating inclusive centres where Disabled and non Disabled children can play and learn together.

Disabled children also have the same desires as non Disabled children to play and have fun. Kids meets these by offering inclusive adventure playgrounds, and holiday schemes that are inclusive of Disabled and non Disabled children. This allows them to improve their social skills, and take part in everyday activities. Kids also runs a youth advocacy programme which helps young Disabled people's voices to be heard; being asked about the services they require and what they want to do is one of the greatest needs of Disabled children and young people.

However, there needs to be more child-centred approaches to addressing their needs – more services to find out what Disabled children – especially those without verbal or apparent communication - want and how they want it accomplished. There need to be more training and events where Disabled children are consulted on matters that affect their everyday life. In a recent survey of parents/carers receiving Kids services, 39% of respondents cited Kids as giving the best support for their child. (The next highest score of 14% was for schools.) Parents tell us that it is the emotional support, advocacy and information they receive from Kids that they need

and appreciate most. Kids have more evidence regarding family support which is highlighted later (see Question 6).

**3. What are the barriers currently restricting access to services and therefore effective intervention?**

The barriers for specialist services that are primarily or exclusively for Disabled children are:

- Financial constraints
- Professionals thinking they know best without due regard to the views of parents and Disabled children and young people themselves.
- Lack of flexibility and choice.
- Low parental expectations.

There are also universal services, which have barriers when trying to encompass the requirements of Disabled children

- Negative attitudes – within society at large and reflected within those of staff, budget holders, insurers, etc.
- Lack of flexibility of statutory services, e.g. around transport
- The gap between policy – often based around the Social Model of Disability, and practice – most often based around the Medical Model of Disability. (This is most clearly defined and explained in Making Connections: developing inclusive leisure in policy and practice by Pippa Murray, pub. 2004, Joseph Rowntree Foundation.)
- Lack of training, especially based on Social Model, child centred practice.

**4. Are services sufficiently co-ordinated at local level to allow families to access sufficient support to meet their needs?**

Within recent years there has been a growing demand for partnerships and coordination between different services in order to offer the best possible solution. However, these partnerships are often on a more national scale, and locally there is not enough consultation between different services. Hopefully with the establishment of Children's Services departments and Children's Trusts in local government, there will be more consultation and coordination to provide a successful multi-agency approach.

Another area where coordination is required is through 'mediation'. Parents and Disabled young people can find themselves in dispute with their Local Authority over a wide range of issues that touch the life of a Disabled child or young person. Mediation services already exist within the Special Education Needs area, and Kids runs nearly all of these within Greater London. These services are highly successful and should be extended to cover all disputes between parents of Disabled children and Local Authorities; parent partnerships should be strengthened.

**5. How does the system of support for Disabled children and their families compare across the country and abroad? Are there lessons we can learn to improve outcomes?**

One exemplary lesson we would recommend for closer examination and possible national replication is Camden Council's family project service which is funded to prevent families reaching the stage where they need social service input.

**6. What family support services i.e. key workers, short breaks, sibling support, behavioural management are currently available and how do these relate to other services?**

Kids offers many different family support services, such as the Early Support Programme, where dedicated key workers help families who have a very young Disabled child. There is also home care support and respite care where families with Disabled children receive help in the home or in residential units. We also offer parental support groups, where information is shared between parents, as well as sibling groups where the brothers and sisters of Disabled children are supported. Parents are happy with the quality of our services, and feel comfortable with the not-for-profit and voluntary sector aspect of our delivery. They tell us they feel listened to and valued, and we meet individual requirements flexibly – offering an explanation of options and choices. We provide the all-so-important emotional support for parents/carers (a vital “value added”), and can give a holistic range of support and advice.

However, Kids believes there should be more home based respite (prevented by a lack of funding), which benefits the whole family. There should also be an introduction of a new profession of Inclusion Worker. Including Disabled children and young people into Universal Services is going to require a great culture change. It is appropriate for there to be professionals who are trained and have the expertise to overcome the barriers and enable this to happen. This will involve more funding for issues such as training, as well as being able to provide resources and further care.

There should also be more focus upon giving families short breaks; Kids provide Weekend Activity Breaks, however if there was more funding these could be more frequent and accessible to more families. The Supporting People funding criteria should be extended to cover temporary accommodation for Disabled children and young people requiring a short break and/or parents requiring respite. Many respite services are under threat as they are very expensive compared with other forms of provision. On the other hand very large sums of money have been poured into the Supporting People Fund which generously funds supported accommodation, but is not available to be used for short break/respite care accommodation. Ironically Disabled young people can become eligible for this funding after 16, as long as it is on a permanent basis. The funding rules should be changed to allow Supporting People to fund shorter periods away from home which could end up being cheaper than providing permanent alternative accommodation before it is really required.

**7. What are the most cost effective interventions in delivering better outcomes?**

If all universal services were to have access to support for training towards inclusion and financial support for creating accessible environments then there would be less need for intervention at a later stage. Problems would be recognised earlier and given appropriate treatment, advice or support. Training such as Disability Equality training should be introduced into schools, extended schools, health services and childcare services.

**8. Are there interventions which, if made earlier, could reduce more costly interventions later? How can we identify the need to intervene earlier?**

One area where earlier intervention is needed is regarding asylum seeking Disabled children. There are few services available at the moment that assess whether they are Disabled, the extent of their requirements and their placement in appropriate services. A family experiencing a genuine fear of persecution in their country of

origin may or may not decide to seek asylum. A family which has a Disabled child and is also experiencing a genuine fear of persecution is much more likely to seek asylum, especially if that child's life chances are likely to be greatly extended by relocating to a country like the UK. Kids services in London and Birmingham make contact with asylum seeking Disabled children in a way that appears to be somewhat random. Services are often received later than could have been achieved within a more systematic system, leading to poorer outcomes. This is a service element that needs to be improved across the sector.

***9. What lessons can we learn from the legal frameworks in other countries that might inform the review?***

Northern European countries and Scandinavia place a much higher importance on 'play', and on the value of play for Disabled children and young people, with widely available inclusive universal services. Also, Children's workers and playworkers are recognised as valuable professionals, who have clear career paths identified. Recent research, 'More School: Less Play' published by Barnados in 2006, shows that there are significant differences between play opportunities in Danish and British schools; with Danish schools offering more outdoor play, 'risky' play opportunities, free play and trained playworkers who offer stimulating activities.

Kids believes in the promotion of play as a major driver for enabling Disabled children and young people to achieve not only all of the Every Child Matters outcomes, but also the "ordinary" lives that recent government policy has started to aspire to. Kids, through its extensive play network of adventure playgrounds and after school facilities, promotes the concept of free play as much as possible, and believes we should follow the example set by these European countries. Additionally, we would propose that local authorities should have a duty to ensure that all Disabled Children experience a full childhood, which includes access to play, access to out door play and opportunities to take risks.

## **Strategy for Youth Services**

### Objective:

**To review the current provision of youth services and support for young people with a view to identifying longer term policy directions that will bring about improvements in the life chances of young people.**

### **Key questions:**

***1. What is the current distribution of youth services and youth engagement activities available across the country? How is that likely to evolve following the Youth Green Paper?***

The majority of Disabled Young People currently access Youth Services via Connexions or through some allocated Youth Service Disability (Inclusion) Officers. In our experience Disabled Young People are often offered youth provision that is separate or segregated (i.e. Disabled Young people only) although they may access mainstream youth club buildings. Often these youth clubs claim to be inclusive by having non Disabled volunteers/ helpers. However, the status of these volunteers is higher than the Disabled Young People and suggests that Disabled Young People always need support from non Disabled Young People. However, Disabled Young People consistently tell us they want friendships based on equal terms with Non Disabled Young People not helpers.

Other youth service provision that Disabled Young People who use our services access is in the form of projects (i.e. theatre/ dance workshops, art workshops, issue based consultations). These projects are often short term with no additional funding to ensure sustainability.

Where inclusive youth service provision exists it is often due to a strong Statutory and Voluntary partnership with the voluntary agency generally offering disability "expertise" whilst statutory workers remain responsible for Non Disabled Young People.

These issues have not been significantly addressed in the Youth Green Paper.

***2. Building on the Youth Green Paper, is there more that could be done to improve and sustain the effectiveness in the delivery of existing services and activities?***

### **Disability Equality Training**

The main reasons why Youth service Staff have told us they feel unable to welcome Disabled Young People has been due to Youth Workers feeling untrained to work with Disabled Young People with significant physical and learning impairments. The training of youth workers to ensure they understand under the DDA and Disability Equality Duty that all provision must be extended to Disabled Young People who have the right to access mainstream leisure provision.

### **Review Staff Structure**

Including Disabled Young People does sometimes require Youth Clubs to review staffing structure and roles, although often these changes are not as huge as first envisaged. Many Disabled Young People can access inclusive environments with

minimal support it is accessing "excluding" environments that impact heavily on additional support levels needing to be in place.

***3. What are the particular barriers faced by different groups of young people, including Disabled young people, in accessing services, and what are the policy issues that arise?***

**Refusal of Access**

Many Disabled Young People that we work with have been formally excluded from accessing services. Some young people have been told this is due to Health and Safety Issues, or staffing ratios, or lack of trained staff, others have been given no clear reasons. One young woman who is a wheelchair user was excluded from a youth club and told to return "when she could walk". This is often in contradiction to Youth Services Equality of Opportunity Statements and is unacceptable in light of Disability Equality legislation.

**Bullying**

Disabled Young People who have successfully attended mainstream youth provision have often been unable to sustain this due to being bullied. Tackling disability is a key policy issue for Youth Services, in the same way as tackling homophobia and racism.

**Adapted and Inclusive Youth Work Curriculum**

In order to meet Youth Matters Outcomes and Every Child Matters Outcomes, it is necessary to look at the adaptation of youth work curriculums to ensure that they are inclusive and will facilitate full participation of Disabled Young People with a range of impairments.

**Access to Buildings**

Youth provision buildings still have access issues despite the DDA, now in its final stage of implementation. Youth Clubs/ services that fail to have basic access via ramps, accessible toilets, and lifts, are still in existence.

**Lack of Support**

Some Disabled Young People do have additional support requirements. These may include information requirements, communication requirements, personal care requirements, medical requirements etc. Youth Services often claim that lack of funds/ training restricts them in being able to meet these requirements.

**Disabled Young People being regarded as being "special"**

One of the major barriers for Disabled Young People is that often youth service provision has been developed in order to act as a respite service for parents and carers. In reality this means leisure activities for a few hours that give carers a break and a young person some fun activities. However, Disabled Young People have exactly the same types of issues that require support from Youth Services. Disabled Young People want youth service support on issues of growing up and the transition from child to teenager to young adult. Through the Young People's Inclusion Network, Kids is developing programmes to support Disabled Young People to work on identity (race, sexuality, gender, culture, religion, disability); supporting young people to develop life skills (keeping safe, making decisions, being involved in citizenship programmes, being heard etc); and developing positive relationships with peers in families and communities.

These are the same issues that Youth Services are best placed to support Disabled Young People on, but currently the majority of Disabled Young People are not able to access these types of services.

***6. What more can we do to support and enable young people to exert a strong demand side influence on provision? What would we expect in return from young people – their rights and responsibilities?***

Disabled Young people are often excluded from existing structures that have demand side influence on provisions including Youth Councils, Youth Parliaments, Youth Group Steering groups. In addition to widening access to these types of structures Disabled Young People should be involved in supporting the development of adapted Youth Work Curriculums, programme development for youth clubs and services, monitoring and evaluations of the impact of these programmes. The development of Disability Equality Schemes will also impact on Disabled Young people influencing demand led provision.