



KIDS is a national charity with a 40 year history of providing an extensive range of services for disabled children, young people and their families.

We currently work with approximately 7,000 disabled children across England with projects supporting children from birth through to 25 years. KIDS is the largest voluntary sector provider of Parent Partnership Services in the country. We also provide SEN Mediation for nearly every London Borough, have several Portage Home Learning schemes and operate both designated and non designated Keyworker services.

KIDS has also had close involvement with the development of Parent Forums and experience of Keyworkers supporting a personalisation pilot. KIDS also provides a wide range of early years provision for disabled children as well as many short break and child care schemes. Our National Development Department has offered inclusion training advice, expertise and publications to a wide range of providers and practitioners across the country for many years.

KIDS welcomes the Green paper as an ambitious attempt to make a real improvement to the lives of disabled children, young people and their families. There is very little in the Green Paper that KIDS disagrees with – our comments are therefore mostly about building on the ideas in the Green Paper to bring them to fruition effectively.

This response is as a result of a number of consultation exercises, including parents and staff involved in direct delivery of services. We have tried to pull it all together in a consistent way – but in different sections you will still hear ‘different voices’ from these different groups.

Rather than using the framework of the specific questions suggested we have grouped our comments under the following headings:

- Assessment;
- Education, health and care plan;
- Personalisation and personal budgets;
- Key working;
- Early intervention;
- Inclusive schooling and the removal of the bias towards inclusion;
- Mediation;
- Learning and achieving;
- Behavioural, emotional and social difficulties;
- Voluntary sector impact.

Assessment

- The process is likely to be complicated and require a high degree of coordination. Keyworkers are well placed to do this but must be adequately trained and have credibility with other practitioners to drive the process forward.
- Getting all agencies to work cohesively together will be challenging and will require a significant change in current practice – the Early Support model has worked in some areas but needs embedding across the country.

- Parents and children/young people's views are integral to the process and need to be taken into full account.
- KIDS parents said they sometimes need information gradually and felt some might find the information from a single assessment process overwhelming, so practitioners/keyworkers will need to be aware of this.
- Advocacy and independent advice is currently available to parents through Parent Partnership Services (PPS). If the PPS remit is to extend through to Health and Social Care duties it is vital that PPS are adequately resourced, staff appropriately trained and the Exemplifications of Minimum Standards given more weight.
- Covering all three agencies there will be even more reason for Parent Partnership Services to be fully independent of all three statutory bodies. Local Authorities should be encouraged to use this change to consider outsourcing their Parent Partnership Services.
- Depending upon the configuration of a 'new' PPS to cover all three agencies, staff currently employed within LA PPS's may have a right to TUPE. There is a very significant obstacle regarding the transfer of LA staff into all but the very largest voluntary sector organisations because of the uncertainty of future pension costs with regard to the LA final salary pension scheme. Most voluntary organisations would not be wise to assume such uncertain liabilities.
- The SEN Code of Practice would need to cover Education, Health and Social Care duties and responsibilities.
- Parents will need clear, transparent information, available in a range of formats.
- Person centred assessments will require a significant attitudinal shift and training will be required across a range of practitioners.
- Adult services across all agencies will need to be part of the process as the disabled young person approaches adulthood – this will need careful consideration and is likely to be extremely complex.
- Assessments need to be portable between local authorities.
- Reassessing children and young people who currently hold a statement of SEN to enable them to hold an Education, Health and Social Care Plan is likely to be extremely challenging in terms of time and resources and may lead to duplication if current needs are being adequately met.
- Parents should maintain the right to request a single assessment.
- Education, Health and Social Care should each be able to request an assessment.
- A single assessment process will require information to be shared across a wide range of agencies. Confidentiality and security of information needs to be assured.
- The Common Assessment Framework is the closest 'thing' in existence to a single assessment. Rather than start from scratch, the new assessment process should utilise the CAF and build on it.
- In developing the new system the opportunity should be taken to utilise new technology from the start, rather than developing more paper based systems. To this end the technology used by national eCAF could be developed for the single assessment.
- The single assessment must not be simply added 'on top' of existing assessments – assessments on their own deliver nothing and simply use up resources. Legislation will be needed to remove some assessments which have a statutory basis and replace them with the new Single Assessment.
- Good practice guidance will be required to ensure that parts of education, health and social care only carry out additional assessments if they are really necessary (not in order to gate keep resources).

Education, Health and Care Plan

- The Education, Health and Care Plan (referred to henceforth as 'plan') will need a statutory context with legal duties across all three agencies to provide for children with SEN and disabilities.
- There should be one point of appeal for parents wishing to challenge the plan.
- The appeal process could be built on the existing SEN tribunal structure.
- With one appeal system through a tribunal process, parents would gain the right to an appeal if the health needs of their disabled child were not being met, but lose the right to judicial review over disputes regarding the provision of social care, to be replaced with a 'one stop' tribunal.
- KIDS parents wanted increased access to advocacy and emotional support for themselves as part of the plan.
- One indicator that a new system is working would be for disabled children to have a plan that leads to provision being in place before starting school.
- Children's needs change over time and the plan will require clear processes for review with accountability across all areas. This process could be based on the action plan which is within the second edition of the CAF and is further enhanced by national eCAF.
- Parents views and aspirations will be vital for children, but if plans are to support the needs of young people up to the age of 25 there will need to be a shift of emphasis and ownership to the young people themselves. The plan will need to 'morph' from something owned by the parent(s) to something owned by the young person.
- Thresholds for the plans are unclear – low thresholds are likely to improve early intervention, higher thresholds may mean some children's needs are not adequately addressed.
- In developing thresholds it would be helpful to utilise frameworks already commonly used elsewhere in the system. These include the ODI classifications for disability (now also used in the national eCAF) and the DLA thresholds. It would also be important to consider thresholds for disabled adults access to services to minimise disruption as a disabled young person becomes an adult.
- There needs to be clear and transparent eligibility criteria for all services.

Personalisation and Personal Budgets

- Clear information, support and training will need to be available to parents to enable them to realise the potential benefits of personalisation. This could be provided by the voluntary sector.
- Independent brokerage support for families is required – a potential role for the voluntary sector in general and Keyworkers in particular.
- Due to current public expenditure constraints many LAs are likely to consider extending contracts with agencies that already provide brokerage for disabled adults to children and families. This should be discouraged as both the needs and the opportunities for children are quite different to those of adults. The disabled children's voluntary sector is in a good position to provide such a service and this could provide a reliable source of income for voluntary organisations as they lose other block contracts.
- However support for young people to take ownership and control of their personal budgets as they move on towards adulthood will be required.
- Anecdotally KIDS has heard that after early promise, the personalisation agenda for disabled adults has in many LAs become less personal and more about a system change. Getting personalisation right for disabled children will greatly transform the expectations of those children and their families as they go into adulthood. Getting personalisation right for disabled children effectively gives us a second chance to transform services for disabled adults.

- Most voluntary sector providers are not geared up to respond effectively to the personalisation agenda. Support across the sector is required to move this forward in the proposed timescales. This includes very practical support as providers transform their infrastructure to allow them to be commissioned on a child by child basis rather than block contracts and grants.
- KIDS is aware that there are very mixed views in the field over personal budgets across Education and Health. KIDS supports the move to personal budgets and feels the difficulties seen by some are not 'show stoppers'.
- Personal budgets should focus on quick wins initially – a good example would be pooling transport cost from Social Care, Education and Health into a personal budget.
- It is relatively easy to see how personal budgets for Education would work for children attending mainstream schools – with the additional funding attached to that child put into a personal budget. It is not so easy to see how it would work for children attending Special schools.
- There will be a real challenge in mainstream schools that have developed (good) highly inclusive practice through the imaginative use of the additional funding attached to children with SEN, that this is not undermined by personal budgets.
- Nevertheless if the additional funding attached to a disabled child in mainstream education has become too remote from that child – then there is little recognition within the system of when that child has progressed and no longer requires the additional support for which the school is funded.
- KIDS knows very little about FE and HE. Nevertheless if personal budgets are available in school, then disabled young people and their families will expect them to be available in FE and HE. How this would be organised we do not know. However there is a potential cost saving here if personal budgets can be used to support disabled young people living at home, or near home and attending local FE provision instead of attending specialist residential FE, usually at some distance from home.
- LAs need to be encouraged to commission on a sub regional basis for services for disabled children – as there will probably be less funding for block contracts due to both public expenditure cuts and more funds being diverted into personal budgets. If LAs do not work together in this way, a disproportionate amount of funding will be used in commissioning and evaluation rather than service delivery.
- Values and attitudes training for staff (both statutory and voluntary sectors) is vital to support this shift in service delivery.

Key working

If all the ideas within the Green Paper are implemented KIDS believes a very significant and enhanced role for Keyworkers emerges, many of whom will need to be designated:

1. To co-ordinate the assessment process for a family with disabled children.
2. To have a role in making the assessment. This would need careful piloting – a Keyworker's relationship with a family may not survive if the Keyworker is also responsible for assessing their child.
3. To co-ordinate all the services and agencies that a disabled child may require.
4. To support a family in deciding what they require from a personal budget and supporting them in managing it on an ongoing basis.
5. To monitor the family's use of a personal budget to ensure it is not misused. Again this would need careful piloting - a Keyworker's relationship with a family may not survive if the Keyworker is also responsible for checking up on how the personal budget is being used.

6. To provide emotional support to families as critical points in their child's life (e.g. after diagnoses, starting school, leaving school etc).

The voluntary sector has already proved itself as being effective at delivering key working for disabled children.

The Green Paper is silent on the question of emotional support for families with disabled children. In KIDS experience this – providing emotional support to families - is one of the important functions performed by our Keyworkers. David Cameron at a KIDS event talked about a very similar area himself when he described the support that he and Samantha received from a KIDS member of staff (not employed as a Keyworker) soon after Ivan was born.

Early Intervention

- Early intervention is crucial to secure long term positive outcomes for children with SEN and disabilities. KIDS is concerned that the Early Intervention Grant has been cut and funding to meet the specific needs of this group of vulnerable children is not protected.
- KIDS experience is that the recent public sector cutbacks have disproportionately hit our Portage services.
- Portage has demonstrated good outcomes for disabled young children – but there is no statutory duty to provide it. Portage should become part of a core offer for families.
- The skill levels of staff within Sure Start children centres need to be developed to meet the requirements of disabled children.
- KIDS parents also felt health visitors require further training in SEN and disability.

Inclusive schooling and the removal of the 'bias towards inclusion'

KIDS fully supports the Council for Disabled Children's response to this issue. In addition we would also like to make the following points:

- At KIDS we offer a range of services, some are inclusive and some are targeted, but our stated vision is "*a world in which all disabled children and young people realise their aspirations and their right to an inclusive community which supports them and their families.*"
- If disabled children are prevented from being a part of their community, of which school is an integral part, then they are being denied the opportunity to socialise and participate in the 'Big Society'.
- The presence of disabled people at all levels in the community brings many benefits, it 'normalises' the perception of disabled people and gives a sense of identity that moves beyond the label of disability as being shorthand for something negative that is to be avoided.
- If a disabled child is expected to only access specialist services, and is not included in mainstream schooling, it is very difficult for them to grow up to be independent.
- KIDS currently support thousands of parents through our parent partnership and mediation services. Our experiences are that many still struggle to secure placements in mainstream settings with adequate levels of support.
- KIDS acknowledges that there is a broad range of views on special schools. But evidence gathered by KIDS demonstrates that successful, properly implemented inclusive practice in education has far ranging benefits for all.

Mediation

KIDS has provided independent SEN Mediation Services since 2002 and we therefore have considerable experience and expertise in this field. Over the last three years approximately 90%

of cases that have been taken through our face to face mediation process have resulted in full or partial agreement. KIDS therefore welcomes the ambition of the Green Paper to promote and increase use of mediation.

- Mediation should always be offered, and more should be done to encourage parents and Local Authorities to use independent mediation both before and soon after an appeal is lodged.
- Mediation should be more widely promoted by Local Authorities and Parent Partnership Services (PPS) to parents and schools. This should take place a lot earlier. It should be widely offered and all parties should be asked to give the Tribunal reasons why they are not prepared to mediate.
- The DfE has a role in ensuring that a clear message is sent to LAs and schools about the value of independent mediation.
- It is clear from the research commissioned by the DCSF in 2008 [Special Educational Needs Disagreement Resolution Services-National Evaluation-DCSF-RR054-ISBN:978 1 84775 243 7] that knowledge of the existence and function of mediation services is not consistent amongst parents, LAs and schools. What is needed is clearer guidance about how mediation sits with PPS and SEND. There appears to be confusion about the differences between mediation and 'information and support' services. Mediation service providers could provide constructive input in the development of this guidance and good practice materials.
- We do not believe that mediation should become compulsory before a parent is able to register an appeal with the tribunal. Mediation by its nature is a voluntary process. However the incentives to encourage mediation could be stronger with it being a normal part of the process which parties have to opt out of.
- It may be possible for SEND to automatically refer parties to mediation so that mediation is seen as part of the SEND process. Automatic referral must not mean that parties are compelled to mediate but it would help to promote the benefits of the process. Once automatically referred, parties could opt out. However, this automatic referral should not delay or impede a parent's right to appeal to SEND.
- One advantage to making mediation the 'default option' would be to address the problem of one party unreasonably refusing to mediate when the other party is willing to do so. But there is little benefit to having parties come to mediation reluctantly, with no willingness to seek resolution. This could be counterproductive.
- Mediation needs to be brought into the process of decision making earlier. If it is introduced just before a parent lodges an appeal it is less likely to be effective than if it were introduced earlier.
- With increased funding being delegated to schools, the reality is that many disagreements arise at school level where provision for the child is at School Action or School Action Plus. At this point the LA may well not have been involved. Schools should have a greater role in informing families about mediation (and PPS) at the point at which they inform a family of a child's SEN.
- KIDS would welcome adoption of the recommendation in the 2008 National Evaluation that a legal duty is placed on schools to inform parents about opportunities for disagreement resolution.
- Schools need to understand mediation if they are to promote it. KIDS provides mediation awareness training to LAs. This needs to be extended to schools but has financial implications.
- Currently, LA participants will occasionally attend mediation without the authority to reach agreement. This needs to be addressed so that parents can have full confidence in the process and see it as a realistic alternative to SEND.

- Mediation Services are funded by LAs. Until 2004, top up funding was provided centrally for mediation. The take up of mediation by LAs was significantly higher as a result of this. After 2004, LAs use of mediation dropped considerably, presumably because it was funded from their own budget. A move to more centralised funding would have three key advantages:
 1. LAs may feel more able to promote a service that is funded externally.
 2. Cost considerations will be far less of an issue in determining the number of referrals made to a mediation service by LAs or schools.
 3. Parents may have more trust and confidence in a mediation service that is independently funded.
- Ideally there should be "joined up" mediation and a holistic approach can work well. KIDS have facilitated mediations attended by Education, Health (e.g. Speech and language therapists) and Social Services (where residential placements have been in dispute).
- The main difficulty is that currently each agency has its own separate budget and works very differently. However this difficulty will have to be resolved if personalised budgets across the three agencies are to work.
- Mediation with the parent and more than one service could be difficult given current structures. Potentially, you could have four or more parties with conflicting interests to mediate between!
- The cost of mediation might be higher but when seen in context of joint working it should minimise duplication of cost and effort.

Learning and Achieving

- It needs to be a requirement that all prospective teachers and support staff have extensive training on SEN and disabilities, with regular inset training and accountability for those who work in schools SEN departments.
- There should be increased recognition for staff who show enthusiasm and expertise in SEN.
- Increased sharing of good practice and innovative work is a positive move forward.
- There is a potential role for the voluntary sector in delivering training to school staff.
- There should be improved information on Parent Partnership Services as a statutory service with an expectation that schools and LA's will signpost parents to their local service for support.

Behavioural, emotional and social difficulties

- The BESD label can confuse the issue surrounding the needs of these young people and label them unnecessarily. Many children presenting with BESD do so as a result of an underlying problem or difficulty, often an undiagnosed SEN.
- Where children and young people are presenting with these difficulties it is vital that the underlying causes for the behaviour are identified and their needs are supported and addressed. If at all possible this 'label' should be temporary until the underlying cause is identified and a more 'precise' designation should then be utilised.

Voluntary sector impact

We have repeated below those bullet points above that refer to this area and then added new points at the end.

Repeated points:

- Covering all three agencies there will be even more reason for Parent Partnership Services to be fully independent of all three statutory bodies. Local Authorities should be encouraged to use this change to consider outsourcing their Parent Partnership Services.

- Depending upon the configuration of a 'new' PPS to cover all three agencies, staff currently employed within LA PPS's may have a right to TUPE. There is a very significant obstacle regarding the transfer of LA staff into all but the very largest voluntary sector organisations because of the uncertainty of future pension costs with regard to the LA final salary pension scheme. Most voluntary organisations would not be wise to assume such uncertain liabilities.
- Clear information, support and training will need to be available to parents to enable them to realise the potential benefits of personalisation. This could be provided by the voluntary sector.
- Independent brokerage support for families is required – a potential role for the voluntary sector in general and keyworkers in particular.
- Due to current public expenditure constraints many LAs are likely to consider extending contracts with agencies that already provide brokerage for disabled adults to children and families. This should be discouraged as both the needs and the opportunities for children are quite different to those of adults. The disabled children's voluntary sector is in a good position to provide such a service and this could provide a reliable source of income for voluntary organisations as they lose other block contracts.
- Most voluntary sector providers are not geared up to respond effectively to the personalisation agenda. Support across the sector is required to move this forward in the proposed timescales. This includes very practical support as providers transform their infrastructure to allow them to be commissioned on a child by child basis rather than block contracts and grants.
- The voluntary sector has already proved itself as being effective at delivering key working for disabled children.
- Schools need to understand mediation if they are to promote it. KIDS provides mediation awareness training to LAs. This needs to be extended to schools but has financial implications.

A few additional points:

- In bringing three statutory agencies together for assessment, planning and delivery there is an obvious need for a third, independent party at many points in the system. The voluntary sector is well placed to be this third party.
- In summary the voluntary sector could:
 1. Co-ordinate (and contribute to) assessment.
 2. Build the Plan.
 3. Support the family to create a personal budget to implement agreed parts of the Plan.
 4. Support and monitor the personal budget as it utilised.
 5. Support families through independent Parent Partnership Services.
 6. Promote and offer independent mediation between all three agencies and the family.
- The voluntary sector is also well placed to develop and provide new services for families. If personalisation is to actually deliver more personal services there will need to be an increased range of options open to families. Voluntary sector organisations with particular niche skills should be encouraged to spread across a range of local authorities rather than hold large block contracts in single authorities.
- Families of disabled children are by definition the younger end of the adult population. These families are increasingly looking to the web for all aspects of their lives. It is important that providers of services for disabled children and their families utilise the web to make services accessible and to deliver them. The voluntary sector is in the lead in this

area and has come together to promote these services. KIDS can be found at www.directshortbreaks.org.uk and the providers working together can be found at www.digitaldelivery.org.uk .

- Another measure of the effectiveness of personalisation will be the greater involvement for disabled children in mainstream services. The voluntary sector is well placed to offer both support to disabled children accessing main stream provision and training mainstream settings to include disabled children. KIDS has particular expertise in this area.

KIDS would be happy to elaborate on any of the above points. In the first instance contact Kevin.williams@kids.org.uk (who may put you in direct contact with a staff member or parent whose has a much greater understanding of the area concerned).