

# Comprehensive Spending Review – Submission to HM Treasury

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## **Evidence from the Office of the Children's Commissioner to the Treasury to inform the Comprehensive Spending Review 2007**

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### **Executive Summary**

The Office of the Children's Commissioner (OCC) welcomes the establishment of the Policy Review and the four sub-reviews and the opportunity to give evidence to inform the Comprehensive Spending Review 2007. Each of the reviews raise a number of issues which are of major concern to the Children's Commissioner, some of which are addressed in this response.

### **Prevention**

The OCC supports strong investment in prevention and early intervention to maximise positive outcomes for children and young people. We commend the provision of universal support for parents of children of all ages, in addition to high quality, non-punitive, targeted support for families with complex needs such those with drug or alcohol addictions and those with mental health problems. Parenting support should be part of broader policies addressing children's needs within a clear overarching strategy, drawing on evidence that parent and family focused interventions can have positive outcomes.

We hold deep concern on steps towards linking behaviour to sanctions, such as proposals to withdraw housing benefit from those evicted due to anti-social behaviour. Such steps may infringe punitively on the rights of children, leading to homelessness, poverty, ill-health, further social exclusion, and poor educational attendance and attainment. We believe that Government cannot reasonably expect "responsible" behaviour from families with complex needs unless it provides such families with appropriate and high quality support to achieve this target.

### **Disabled Children**

The OCC is delighted that the needs of disabled children, who are often neglected, have been recognised through this separate sub-review. The complexity of this area, and the observed rise in numbers of some diagnoses, indicates the need to identify and establish sufficient capacity to cater for need. This includes issues such as autism and foetal alcohol syndrome. There is a need for a suitable performance target to ensure delivery of the five outcomes for disabled children.

It is disappointing that there is no obvious scope within the cross-cutting reviews for consideration of Child and Adolescent Mental Health Services (CAMHS) when mental health has significant impact on all five ECM outcomes for children. It is imperative that CAMHS is not diminished in both terms of investment or commitment, with children receiving services in age-appropriate settings. This will never be more relevant than for children who offend and have concurrent mental health problems. It is imperative to end

the incarceration of young people with signs of psychosis or serious learning disabilities.

### **Youth Services**

The views of young people are critical to all aspects of this review, yet there is a problem with services either not being accessible or appropriate. Asking children and young people what works, is an efficient and cost effective investment, resulting in targeted services that better meet their needs. Appropriate mechanisms need to be in place to gauge their views, and adequately respond. Children and young people deserve to be seen as full members of their communities.

### **'High Cost, High Harm Families'**

Finally, we must be mindful of the risk of stigmatising parents, children and young people by categorising them as high risk, high harm families. Employing such language conveys a negative image, which influences the criteria that are developed to categorise families in this way. There are families where children are less likely to reach their potential yet we should not be dependent on predictive methods which are untested and accompanied by risks. It is essential to establish supporting parents as intrinsic to the assessment of service provider's performance, implementing a PSA target reflecting resource allocations between adult and children's services, to genuinely address the needs of parents and the issues affect their ability to parent.

## **B1: Prevention strand of review**

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### **Every Child Matters**

Many of the initiatives that have taken place under the *Every Child Matters* banner are relevant to effective prevention strategies. Although these are welcome, it is too early to assess the impact of changes such as the development of Children's Centres, the structural changes introduced by the Children Act 2004 and the responsibility for improving children's wellbeing set out in section 10 of the Children Act 2004.

### **Parenting Support**

The OCC support strong investment in prevention and early intervention to maximise the positive outcomes for children and young people. There is abundant evidence to confirm that the influence of parents on their children's lives cannot be overstated. *Support for Parents, the best start for children* sets out several of the policy initiatives in hand to address this area including the measures in place to reduce child poverty and its impact to which the Government is strongly committed. This was also recognised in the *National Service Framework for Children, Young People and Maternity Services* (2004). The OCC are very concerned that there has been so little progress in implementing Standard 2 of the NSF on Supporting Parents, which provide a standard for inspection against which local services should be held to account. The lack of reference to Standard 2 in many of the documents emanating from Government since publication of the NSF (such as the *Respect Action Plan* and *Support for Parents*) is a missed opportunity as it summarised succinctly the key evidence-based interventions which are needed to support parenting throughout the different stages of childhood. Many of these are included in the *Social Exclusion Action Plan*.

### **Tensions in Parenting Policy**

The OCC are concerned about the growth in parenting interventions and programmes and the near-explosion in the media of 'expert' parenting advice. These are developing without a clear overarching strategy and infrastructure along with a lack of rigorous evaluation of their effectiveness.

Moreover, there is a tension in the current government's approach to parenting support. On the one hand there is the parenting support that is prescriptive, punitive and interventionist, for example: Parenting Orders and the expansion in parenting support promised by the Respect agenda. On the other hand, parenting support as a universal right which is empowering and respectful of parents. The OCC would prefer the development of services that are non-stigmatising, for parenting support to be part of much broader policies for addressing children's needs and would like to see more attention and investment to be accorded to this latter approach.

## Effective parenting programmes

A major NFPI review<sup>1</sup> identified that there is evidence that both early and later parent and family focused interventions can have positive outcomes. It recommends that to achieve maximum benefits, programmes should combine a cognitive component, the teaching of behavioural techniques and a therapeutic approach that offers warmth and understanding. Research has also found that the most important element in parenting programmes is the helping relationship that is established, aided by the skill of the practitioner<sup>2</sup> and the quality of the initial assessment,<sup>3</sup> rather than the content of the programme.<sup>4</sup>

There is evidence showing how broader programmes that influence and engage with parents and children at home, school and the wider community, have the largest and long lasting effects, addressing people's needs for material, practical and parenting support. However, if a family is being overwhelmed by a wide range of problems the capacity of the parenting programme to help is inevitably diminished. It has also been found that to be effective parenting programmes need to ensure they do not create dependency or stigmatise the parents involved and last long enough for positive changes to be sustained. One study found that at least 8 to 10 sessions, or 20 hours, are needed to make a significant impact.<sup>5</sup>

## Support as children grow up

It is self-evident that the type and arguably the level of support parents need changes at different stages of the child's life, including before birth. There has been a major focus on services provided in the early years of a child's life, including child care, but this has arguably not been matched by an increase in provision for parents who need support as their children grow up.

In particular, research<sup>6</sup> has highlighted the lack of support for parents of teenagers. As children grow older there are fewer services available and there is very little preventive work taking place with this group. A common theme from the research is that parents find it hard to access support at a time when they need it and support is only forthcoming when issues reach a crisis. Linked to the lack of preventive, universal services, is the stigmatising nature

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<sup>1</sup> Barrett H (2003) *Parenting Programmes for Families at Risk – A Source Book*, NFPI

<sup>2</sup> Crowley M (2003) *Which programme is best?* Parenting Education and Support Forum.

<sup>3</sup> Henricson C et al (2000) "Parenting in the Youth Justice Context" *The Howard Journal of Criminal Justice*, 36, Vol 4.

<sup>4</sup> Luborsky L (2002) "The Dodo bird verdict is alive and well- mostly" in *Clinical Psychology: Science and Practice*, 9(1)

<sup>5</sup> Patterson G et al (1992) *Antisocial Boys*, Castilia Press

<sup>6</sup> Trust for the Study of Adolescence (2000) *Support Services for Parents of Teenagers: A regional review*, TSA

National Family and Parenting Institute (2001) *National Mapping of Family Services in England and Wales*, NFPI

Allard A (2003), *'The end of my tether': The unmet support needs of families with teenagers – a scandalous gap in provision*, NCH

of the limited parenting support that is available. Family support needs to be normalised for parents of older children.

### **Vulnerable Groups**

There are particular groups of parents, with extreme vulnerabilities, where there is real concern about their ability to enable their children to achieve the five key outcomes in Every Child Matters. The OCC is particularly concerned about the needs of children whose parents have significant mental health or drugs/alcohol misuse problems who now account for a very high proportion of those for whom Local Authorities are initiating care proceedings. The particular needs of this group are referred to in more detail in the evidence relating to the Review on High Cost, High Harm families.

### **Sanctions**

The OCC are very concerned about the moves to link behaviour to sanctions, for example, the proposal to withdraw housing benefit from tenants who have been evicted due to anti-social behaviour. Our particular concerns include:

- The threat to the welfare state in the UK – by allocating provision based on behaviour rather than need.
- The lack of evidence that the threat of loss of housing benefit will compel evicted tenants to comply with forced rehabilitation nor that any form of forced rehabilitation would be effective in reducing anti-social behaviour. As a result of mental health problems or drug/alcohol addiction, a significant proportion of those who may be evicted for anti-social behaviour will have little or no control over their behaviour, thus eliminating the impact of compulsion.
- The risk to the rights and well-being of children and young people affected by this proposal. Potential negative outcomes include: homelessness, poverty; ill-health; further social exclusion; and poor educational attendance and attainment.
- to the risk of undermining many of the very constructive policies of Government in recent years on social exclusion, tackling child poverty, health, education and the Every Child Matters framework.

## **What the OCC would like to see**

We would like to see greater investment in prevention and early intervention that is neither punitive nor driven by sanctions but instead focused on involving and engaging parents and children to help devise holistic support for families and children with complex needs. High quality and durable support is essential; without such provision it is unreasonable for the Government to demand “responsible” behaviour from families with complex needs and thus shift the onus to those in already vulnerable situations.

In relation to families engaged in anti-social behaviour we still believe the focus should be on preventing such behaviour by identifying its complex root causes and by delivering an array of voluntary support and development services to provide long-term solutions.

The lack of an overall family policy strategy within which to develop parenting initiatives has contributed to the uncomfortable dichotomy between “supportive” government policies aimed, for example, at providing voluntary universal service and those more “punitive” and hard-edged policies such as Parenting Orders. We commend:

- The creation of a family support infrastructure for parents of children of all ages, not just those with under-5s;
- Access to help and support for children and parents when problems first occur, not just when they are in crisis; and
- An approach that builds on the Sure Start model and the development of Children’s Centres to ensure this universal support is available in every locality in England for parents of children of all ages.

## **Child and adolescent mental health services**

### *Omission of CAMHS*

The OCC is disappointed that there is no obvious scope within the cross-cutting reviews for consideration of Child and Adolescent Mental Health Services (CAMHS). In submitting this evidence, the OCC stresses the need for ongoing and sustained investment in CAMHS under the overall preventive services strand, while at the same time recognising that it is equally important and relevant to each of the sub-reviews, particularly the Review of Disabled Children given the high incidence of children with learning disabilities and mental health problems.

### *Background*

Mental health is known to have a significant impact on all five ECM outcomes for children. In recognition of the enormous unmet need and the serious consequences that would result in terms of children reaching adulthood with poor mental health, the Government has made funding available during the

period covered by the previous CSR, by setting a specific PSA target on the development of a comprehensive CAMHS in every part of the country.

### *More Improvement Needed*

Having the PSA target with additional funding along with a raft of initiatives across Government (including making CAMHS an integral part of the *Every Child Matters* programme and a standard in the National Service Framework for Children, Young People and Maternity Services), has helped improve the capacity of CAMHS services. There has also been growing recognition of the need for partnership working and for mental health services to be delivered in non-stigmatising settings.

However it needs to be recognised that CAMHS services started from a very low base-line and there is still considerable unmet need and much improvement required. We are concerned that the achievements that have been made in the last few years thanks to the investment into CAMHS and the hard work by many committed people could be lost due to the financial climate within the NHS and, with the targets ending this year, to agencies turning their attention elsewhere. The development of CAMHS, so that it meets the mental health needs of children and young people, will have a significant impact on the success of many of the Government's other priorities. Thus it is imperative that CAMHS does not lose out other services both in terms of investment and commitment.

### **Age Appropriate Services**

There has been some progress towards the delivery of age-appropriate services with far more 16 and 17 year olds being treated in adolescent facilities than before. The OCC has commissioned research to explore the journeys of young people who have been treated in adult mental health in-patient facilities (including forensic units). This research has yet to be published but the early findings suggest that many of the young people who have been treated in adult facilities, some of whom have extremely complex needs, have had varied experiences of services. Although there may be some circumstances in which young people will continue to require admission to adult facilities (e.g. because of distance away from a suitable bed in an adolescent unit, particularly in an emergency), the OCC would like to see the routine use of adult beds being phased out altogether in line with recommendations made by the Mental Health Act Commission and the Government's responsibilities under the UN Convention on the Rights of the Child<sup>7</sup>. This research will be made available to Treasury and key Government Departments when complete.

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<sup>7</sup> UN CRC article 37 - 'Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances.' This is the provision where the Government has made a reservation – "where at any time there is a lack of suitable accommodation or

## **Mental Health of Children and Young People Who Offend**

The OCC is particularly concerned about the mental health of young offenders and intends to tackle this both in its own work programme and also in the forthcoming report to be submitted to the UN Committee on the Convention on the Rights of the Child. It is evident that too many children and young people are being incarcerated in England rather than supported, with the consequence that there is a very high recidivism rate and many young people going in and out of custody - a pattern which is then likely to repeat itself in adult life.

Although the Government hopes to tackle this through preventive work, the OCC considers that urgent action should be taken to address this problem and, in particular, the 10% or so of young people in custody who are known to show signs of psychosis. Such young people should not be in custodial settings and require evidence-based, high quality treatment. Similarly, the significant proportion of young people with serious learning disabilities in custody should be found alternative placements.

We would like to see more investment in alternatives to custody for all children and young people, with initial priority being given to those with mental health problems. More effective and long-lasting positive outcomes will be achieved by moving resources from custody to alternatives such as restorative justice, treatment foster care and community sentences. Effective through-care and resettlement are critical to achieving and sustaining improved outcomes for young people in custody, in particular, those with mental health problems. The Youth Justice Board has established Resettlement and Aftercare Provision (RAP) in 50 Youth Offending Teams. The core RAP provision provides up to 25 hours of planned support and activities each week, on a voluntary basis, including:

- ongoing access to substance misuse and mental health treatment
- support to access accommodation
- education training and employment
- positive use of leisure time
- peer and family support work.

Early evaluation of the RAP schemes is positive and the support is having a positive outcome on young people's lives and on preventing them from re-offending. The OCC would like to see more funding made available to ensure the national roll-out of RAP schemes.

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adequate facilities for a particular individual in any institution in which young offenders are detained, the UK reserves the right not to apply article 37(c) in so far as those provisions require children who are detained to be accommodated separately from adults."

### **What the OCC would like to see**

Early intervention with CAMHS support may help to prevent more serious mental health problems from developing in a child, or a family becoming unable to cope. What the OCC would therefore like to see in CAMHS as a result of the CSR is:

- A planned continuation of the ring-fenced Local Authority grant from 2008;
- A continued commitment to developing **and maintaining** a comprehensive CAMHS service;
- Expansion of the evidence base where required and continuing investment in clinical effectiveness products to include appraisals and clinical guidelines on, for example, Multi-Systemic Therapy. There is emerging evidence of effective interventions but these need to be piloted and evaluated – these things take time – but are worth the investment of time and resources;
- A restatement of the progression of the target to a standard which continues to apply across the NHS;
- A sharper focus on inspection of CAMHS by the relevant new inspectorates;
- A commitment to sustained investment until the target is reached in all areas with action taken through performance management to address areas where the target has either not been met or where there may be possible disinvestment planned;
- A specific commitment from the government to tackle the mental health of young offenders and to stop the incarceration of young people with signs of psychosis or serious learning disabilities; an
- Investment in Resettlement and Aftercare Provision for young people leaving custody

### **Thresholds for intervention in social care**

The OCC is concerned that there is lack of adequately qualified social care staff and that this is already having a major impact on the lives of vulnerable children and young people. The report of the Joint Chief Inspectors published last year found that there were many authorities with children and young people on the child protection register who were not allocated to a social worker. It is difficult to see how the Government will be able to fulfil the ambitious goals of *Every Child Matters* if there is insufficient capacity to meet existing, let alone future, need given the Government's stated intention to lower thresholds to allow for earlier intervention in families with a high level of risk.

Although there is a comprehensive workforce strategy in place which is intended to underpin *Every Child Matters*, services in some authorities are thought to be near crisis point in terms of thresholds for intervention. This is

something that needs to be tackled through the CSR with specific targets set which would lever the change that is needed. The OCC strongly supports the idea that has been mooted of having a target on safeguarding, though only if a target can be found that would not set perverse incentives in this difficult area.

### **Other preventive services**

The Review seeks to examine the impact of more preventative services and early intervention on the life chances of children and young people and on the value for money of public spending on children, young people and families.

There has been some commitment to increasing the number of the school nursing workforce so that there is one full-time nurse per secondary school and its cluster of primary schools. School nurses provide key interventions that address many aspects of the Government's agenda, including tackling teenage pregnancy, provision of counselling for children who need it (an essential part of tier 1 CAMHS) and reducing school absences with a flow-on effect to reducing the number of children out of education, employment or training. It is not yet known to what extent this aspiration has been reached but the OCC would like to see more investment in this important area given the major contribution that school nurses can play in prevention.

## **B2: Review of Disabled Children**

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The OCC is delighted that the needs of this frequently-neglected group have been recognised through this separate sub-review. Disabled children and young people is one of the key themes for the OCC's current work programme - the OCC intends to work directly with a wide range of disabled children and young people and ensure that their views are embedded in all of its work and used to inform dialogue with key decision-makers.

The Office of the Children's Commissioner has conducted a session with the National Autistic Society where we asked children, young people and parents affected by autism and Aspergers for their views on where services need improvement, and how best to achieve this. This document is reproduced in full and is attached at **Annexe 1**.

### **Changing Profile of Disabled Children**

It is important that the changing profile of disabled children is considered very carefully for the CSR given that it will impact on the particular types and patterns of services that families with a disabled child will need in the period to be covered by the Review. New developments, particularly advances in medical science, have improved survival chances for those babies born pre-term. However, those born pre-term have a higher chance of having a disability of some kind, and total numbers of disabled children are rising accordingly. This group, which will include low-birth weight babies – are frequently found in areas of disadvantage, and yet many will receive inadequate follow-up after an intensive period of hospital care following delivery. Of the babies born weighing less than 1500 grams, up to fifty percent will show later cognitive development. It is critical therefore, that these children receive an adequate and agreed level of support active from the moment they leave hospital for a minimum follow-up period of 6-months. They should also be a key target for local Sure Start programmes.

Furthermore, the rise in numbers diagnosed as being on the autistic spectrum, for example, will impact directly on the numbers of families requiring short breaks which are essential to enable families to cope. Failure to establish sufficient capacity in this area will lead to more families being unable to cope and a higher rate of family breakdown with all that that entails.

In all services for disabled children, it remains essential to recognise the expertise of families, children and young people directly affected by disability, and for their critical input to receive equal value alongside professional services and opinions.

### **Foetal Alcohol Syndrome**

The rise in the number of children with Foetal Alcohol Syndrome (FAS) should be considered as an area requiring greater attention and research: enabling a thorough needs assessment to determine suitable areas for action and determine the level of funding required. The incidence of Foetal Alcohol

Syndrome is now estimated to be 1 in 300 infants, comparable to the incidence of Down Syndrome standing at 1 in 666 live births. Children with FAS will have a subtle mix of impairments among which are: cognitive, memory and attention impairments, growth deficiencies and behaviour posing challenges to mainstream school staff.

However, these impairments themselves may be at such a level that when assessed in isolation they will fail to meet thresholds for specialist intervention and thus support. Moreover, failure to adequately identify their needs risks misdiagnosis, such as interpreting symptoms as ADHD and offering inappropriate services as a result.

Further evidence is therefore urgently needed to determine the numbers of children born with this condition. We must look also, to the origins and nature of alcohol abuse in our society generally – to prevent the instance and prevalence of this condition. In summary, it is critical to gain a complete picture of the specialist educational needs of children affected by this syndrome.

## **Child Care**

Accessing affordable and high quality child care is also more difficult for families with disabled children. Further resources are needed to ensure that parents with disabled children are able to access these services in the same way as all other parents and to have as wide a range of choice of provision as other families.

## **Comprehensive Service for Disabled Children Target**

In the absence of ring-fenced funding for services needed to support the families of disabled children, the OCC would like to see changes to the targets to be put in place following the CSR. The CAMHS target has been highly successful as a lever for change in that it has undoubtedly led to a very significant increase in investment in services for children with mental health problems. The OCC would like to see a comparable target for the families of disabled children, which specifies what is meant by a comprehensive service for disabled children, to include:

- affordable and accessible child care;
- adequate provision of short breaks as an entitlement;
- a more comprehensive benefits system that recognises the huge disparity in costs between families with a disabled child and other families;
- the provision of a key worker where needed, depending on the complexity of the services required;
- an entitlement to a comprehensive assessment and evidence-based, high quality interventions to be available in line with assessed need;
- an extension of Direct Payments where these are not available; and

- more rapid provision of aids and adaptations to enable disabled children to lead as normal a life as possible including provision in school where appropriate.

The OCC feels that the setting of such a target is the only real way of leveraging change that is going to be needed if the Government is to deliver on the five outcomes for disabled children and young people and to make Every Disabled Child Matter.

### **Communication or Language Difficulties**

One area where there is both unmet need and variations in service provision is in children who have communication or language difficulties. Each child who starts school with poor linguistic ability compared to his or her peers is unlikely to be able to participate fully in either the academic or the social side of school. Greater investment in specialist therapy services is therefore needed as part of the overall early intervention strategy, delivered in early years settings wherever possible.

There is still a lack of equity in the provision of such services despite excellent practice in some areas which have reduced long delays through better use of skill mix. However, more capacity is needed if we are to tackle the unmet needs and to ensure that all children are ready for school.

#### **What the OCC Would Like To See**

- Children with autism or Aspergers to be supported through appropriate education placements, in an environment where teachers are informed and sensitive to their needs;
- All low-birth weight babies to receive an adequate and agreed level of support active following hospital discharge for a minimum of 6 months;
- With the numbers of children born with Foetal Alcohol Syndrome rising, this must be considered as an area requiring greater attention and research: enabling a thorough needs assessment to determine the most appropriate means of supporting children and families, backed by appropriate levels of funding;
- Childcare should be accessible by the parent's of disabled children without disadvantage or additional cost;
- To ensure that every disabled child matters by establishing robust and meaningful performance targets to ensure the comprehensive delivery of services;
- Children must be provided with appropriate communication aids to ensure they can participate in both academic and social opportunities to the full.

## **B3: Strategy for Youth Services**

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### **Involving Young People in Services**

From the OCC's experience and from the views that young people have expressed, there is a problem with services either not being accessible, not being perceived as appropriate or not meeting young people's complex needs. The OCC believes strongly that imaginative approaches to involving children and young people are an essential pre-requisite to securing successful outcomes. Asking young people what works, and involving them on an ongoing basis in the design, delivery and evaluation of services is key to the effective delivery of services.

There is much evidence, including that established by the Social Exclusion Unit,<sup>8</sup> that a child/young person-centred approach is required in order to effectively address multiple and complex needs. Policies and services that take the views, thinking and behaviour of young people into account are much more likely to be successful. The SEU Transitions report<sup>9</sup> found that young people's view of the ideal service is one that is joined up and employs staff that understands them, respects them and is prepared to listen. They were also keen for those involved in the delivery of services to see them as a person rather than a problem. Being listened to and involved in services and decisions that impact on their lives is a consistent message that children and young people tell the OCC. (See attached MORI poll data – please note this information is embargoed and to be treated as strictly confidential.)

### **Holistic Services**

The OCC supports a holistic approach to service delivery for young people. There is increasing recognition that many young people have multiple and complex needs.

However, many young people are either having to use a number of services to have their needs met or else are not using existing services, for a range of reasons including lack of information, access problems or perceptions of the service as inappropriate.

For those young people who are linked in to a wide range of services there is a recognition that many of them can end up lost between services with no one service prepared to take responsibility. For those young people reluctant to take up any offer of services, some effort is required to persuade them of the benefits of using the service. For both these groups of young people, a more effective approach to service delivery is the provision of a range of services at the one project. For example, young people who have left care may be linked in to a leaving care service where they have built up trust with the worker and

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<sup>8</sup> Breaking the Cycle: Taking stock of progress and priorities for the future, A report by the Social Exclusion Unit (2004) Office of the Deputy Prime Minister; Transitions: Young Adults with Complex Needs, A Social Exclusion Unit Final Report (2005), Office of the Deputy Prime Minister.

<sup>9</sup> Ibid

are not keen to use other services. A positive approach is for the leaving care project to link in with a wide range of other services, including specialist support e.g. drug support, psychiatric nurse support, and for these services to be provided at the leaving care project.

It can be daunting and confusing for some young people to have to deal with several different agencies at once. Effective partnerships and 'holistic services' such as one-stop shops offering young adults help and advice on a range of problems can make a difference. We support the call in the SEU Transitions report for 'an effective and coordinated preventative multi-agency response' to ensure that the needs of young people with complex problems are met.

Holistic and joined-up multi-agency services can also help to overcome access issues, make it easier for young people to know where to go for help; and can also overcome the stigma associated with certain kinds of services. Services need to be accessible at convenient times and locations, as well as being culturally appropriate and free of stigma. Other research also suggests that services with an open access policy often work well; and that policy makers should place greater importance on 'one-stop' services for young people. Many young people live unsettled and fast-changing lives so, for example, keeping appointments is not always easy for them. The style of services is critical to their accessibility and there is a need for services specifically designed for young people (with their active involvement, as mentioned earlier).<sup>10</sup>

### **Non-stigmatising Services**

Young people can be reluctant to use services that stigmatise them or label them as having a problem, be it drugs or mental health, and it is more likely that they will take the support offered by specialist workers in a setting where they feel comfortable and are with other workers they trust. There is a greater potential for early intervention, support and preventing an escalation of difficulties if services are seen by young people as something for them, without their feeling they have to fit into a narrowly defined category of need which they not identify with.

### **Trusted Adult**

The importance of a trusted adult in the lives of young people has been mentioned by those working with this group and in research. According to the SEU<sup>11</sup> the role of the trusted adult has two main elements, to build and maintain a trusting relationship and advising and encouraging young people through small significant steps towards positive outcomes. They could be a personal advisor, key worker, mentor or independent visitor and ensure continuity of support and promote trust between young people and services. The OCC supports the development of the trusted adult approach and it is

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<sup>10</sup> Howarth C & Steer C, 2000, Sidelined: Young Adults Access to Services, NPI

<sup>11</sup> Transitions, Social Exclusion Unit Report, op.cit.

important there is continuity in support from this person until the young person no longer requires it.

As the SEU Transitions report found in their interviews with young people,

*Young adults thought it was important that all the service providers they worked with treated them with respect, and listened to their views seriously; but they set particular store by having someone who really cared about them and their difficulties, and who was prepared to work with them consistently to address their needs.<sup>12</sup>*

It is critical that services hear this and put effort into ensuring that a trusted adult is available to those young people in need.

## **Sustainability**

Another major concern of the OCC is sustainability. It is essential that services and programmes are adequately resourced, long lasting and sustainable.

## **Young People's Views**

A key focus of this current review is on youth services and youth engagement activities. While, due to the tight deadlines, the OCC were not able to consult young people directly for this review, we believe the views of young people for the consultation on Youth Matters will also be relevant here.<sup>13</sup> The young people we consulted with included: young people in public care and those who have recently left; young people who offend; young carers; young people attending pupil referral units; young people in secondary education attending comprehensive schools, Enterprise College and a Technology College; young people who truant or present challenging behaviour; young people of BME groups.

## **Services Young People Want**

The young people we consulted identified that what they want is a place to meet that is flexible and caters for a range of young people's interests. They are happy for the service to have an adult presence but it should not be heavily supervised and that young people should have a major input into its management and organisation. The young people mentioned the following as the service they wanted to see:

*"A place you can go where there is supervision" but not "teachery".*

*"It would have to be big for a start; little youth centres get packed."*

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<sup>12</sup> Ibid, p.73

<sup>13</sup> Consultation with Young People, Green Paper – Youth Matters, (2005) A Report for the Office of the Children's Commissioner, NCB

*“Somewhere to hang around, not to do anything in particular and would have to be fun.”*

*“There should be other things going on because in most youth clubs there is nothing for girls.”*

*“A place to hang out where Police and Support Officers don’t move us on and break up friends.”*

Some young men identified this as a safe environment to pursue other interests that usually brought them into conflict with the Police, for example, driving vehicles in public places.

### **Involvement in activities**

The young people we consulted identified that they are involved in a range of activities from organised to informal pastimes. Popular activities included sports (football, swimming, water polo, cycling, tennis, gym, outdoor pursuits and motor sports) and attending youth clubs (either in the club or hanging around outside). Young women tended to prefer learning musical instruments, singing, drama, dance and making music. Few of the young people are involved in nationwide organisations such as cadets, Scouts or Guides, etc.

Informal activities, typically “hanging out” with friends, were a common pastime for most young people, particularly those not involved in organised activities. Meeting friends on the street or in parks, going shopping, attending music events, or staying at home was typical. A significant number of young people said there was nothing going on in their area or no places they could meet friends. Some complained there was nothing to do if you did not like sports.

*“We just do laps around the town.”*

*“Jammin’ on the streets or walking up and down doing nothing.”*

*“The only thing that goes on round here is nicking cars and smoking dope”*

Many young people would welcome the opportunity to participate in a wider range of affordable activities such as dance groups, music making, playing a musical instrument, drama, paint balling or Quasar, motor sports, activity centres, an indoor centre for young people, local cinema, a graffiti park, them park, ski slope, rock climbing, ice skating rink, skate park, cycle paths, internet café, residential experiences, access to a shopping centre, separate youth clubs serving under 16s, over 16s and young women, organised parties and music festivals. An extension of sports provision to include more sports centres and access to a wider range of sports such as wrestling, kickboxing, martial arts (and self defence) and basketball were identified.

*“..the opportunity to try out something different to see if it’s a good choice.”*

Young people said they felt stigmatised by the negative perceptions of young people, particularly where anti-social behaviour dispersal zones are in place and there appear to be few, if any alternatives, to being on the street.

*“You get stereotyped”*

*“Adults should remember they were kids once.”*

They expressed strong feelings about their treatment by adults.

*“Something needs to be done about the way young people are treated on the streets, we are not criminals.”*

A significant number of young people feel unsafe on the streets and fear personal violence or robbery.

Young people from minority ethnic communities spoke of their experience of racism outside their neighbourhood, which inhibits their activities.

*“Wherever we go, like with a couple of people, it’s like, Oh Asians! It’s swearing and like you’re a terrorist.”*

Many young people identified the cost of activities as a significant constraint on wider participation in activities. In addition, outside London, expensive and inadequate public transport inhibited some young people.

*“We have to hang out around the streets and parks, ‘cos we can’t afford to hang out anywhere else.”*

*“A decent bus service and discounted or free transport is important.”*

This is particularly the case for post 16 year olds who have outgrown “youth” provision and are developing adult interests, which are unsubsidised or provided by the leisure and entertainment industry at a commercial cost.

*“Everything you want to do is too expensive. Some young people turn to crime.”*

### **Listening to young people**

A key message from the young people was that they felt their views were not listened to or taken seriously and rarely acted upon. Generally, the participants were critical of central government and local authorities’ attitude to listening to young people.

*“Adults just want to do choices for us – they don’t want to listen.”*

*“Listen to us we have something to say and can help you.”*

The young people were inventive in suggesting ways to communicate with central government and local authorities. Suggestions included: representative conferences with delegates from all schools and age groups; young people attending council meetings or a shadow cabinet of youth councillors for young people’s issues; always asking for a young person perspective when making decisions; young people’s newsletters; local radio station for young people; better publicity of services; visits to schools by councillors and MPs to explain policy; peer group interviews; multi-media, drama and music workshops; involving organisations that have experience of eliciting young people’s views. A further suggestion proposed training young people in communication techniques.

*“They should set up an organisation run by kids and older youths and correspond with them.”*

*“When you are listening to young people, action needs to happen fairly soon afterwards, or else it is meaningless.”*

A group of young people who recently left public care were embittered by inconsistent consultation with them on personal issues, such as Child in Care Reviews, placements and pathway planning. They were not confident their voice would be heard as young adults and doubted positive change.

*“People sit there and talk as if you are not there.”*

In the views of the children and young people consulted, the issues that central government and local authorities should be addressing were wide ranging.

For the post 16 groups concern centred on: money, for example, the level of benefits and everyday costs; student grants and student debt; good quality housing; consistent advice on further education; better work experience and more effective advice on searching and obtaining jobs; underage drinking; the lack of affordable activities and places to hang out appropriate to their age and maturity; treatment of young people by the Police; and finding an effective and innovative way of having their voice heard.

The Key Stage 3 and 4 groups were primarily concerned about: personal safety and the proliferation of guns and knives; stopping class A drug use in their neighbourhood; their relationship with Police and not being stereotyped; and provision of activities throughout the year rather than just during the summer.

### **What young people and the OCC would like to see**

- The OCC would like to see increased investment in sustainable provision for young people. In particular, we would like to see services for young people that are personalised, flexible and allow them the necessary independence with a built in 'safety net' when required;
- We would like to see a more innovative multi-agency approach to working with young people, particularly those with complex needs and for professionals to come out from their silos to work together to better meet their needs. For example, the one stop shop approach or bringing specialist services to young people;
- A key starting point for improving services for young people is to listen and engage with them in identifying what works and involving them in the design, delivery and evaluation of services. Young people feel central government and local authorities should put in place structures to enable them to fully participate in the formation of policy and delivery of services. They want to be heard and treated as responsible young adults;
- The role of a trusted adult is key and having someone who cares and is prepared to stick by them is important to young people;
- Young people want consistent, on demand, high quality, confidential, knowledgeable advice and information services which are sensitive to individuals' needs;
- Young people want a 'Safe Place To Go' – they are aware of adult disapproval of their presence on the streets and concerned about their relationship with the Police, as well as worried about their personal safety on the streets. Many young people mentioned wanting a place "just to be", which is off the streets, provides activities and is lightly supervised by adults, where they are the major stakeholders. Young people asked for activities and environments appropriate to their age; and
- Young people are very concerned about the degeneration of their neighbourhoods and the absence of a sense of community. Much more needs to be done to ensure young people are involved, included and seen as full members of the community.

## **B4: Review of High Cost, High Harm Families**

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### **Predicting Risk**

It is not entirely clear on what basis families are defined as 'high cost, high harm'. The OCC's view is that there is a risk of stigmatising families if criteria are developed that will categorise families in this way. There clearly are families in which children are less likely to fulfil their potential and, although there is recent evidence that such prediction is feasible, there are risks in relying on this. A child or young person who is thought to be at risk may be treated differently in which case it may become a self-fulfilling prophesy.

The OCC is concerned about the increasing use and piloting of systems such as RYOGENS which predicts young people who may be at high risk of offending behaviour.

The following three concerns should be considered carefully before rolling-out these type of predictive technologies: Firstly, is there sufficient evidence of their effectiveness? The assessment tools and information systems which are at the forefront of predictive interventions have not been subject to extensive public evaluation. Evidence of ASSET's predictive accuracy is sparse. More fundamentally, we have yet to see adequate external evaluation of how successful ASSET and ONSET have been in triggering interventions that have met children's needs.

Secondly, do they have a negative impact on children's rights? Systems which encourage multi-agency 'pooling' of evidence from several sources may infringe children's rights to confidentiality. In some early piloting of RYOGENS, there was a strong assumption that information should be shared whenever possible, even if consent was withheld. To facilitate this, a drop-down menu of legislative options was available on the database from which a practitioner could select. The consequence of this approach was misapplication of the law and inappropriate sharing of information. Although systems and management procedures have been tightened, we are still concerned that systems, predicated on pooling of relatively low-level indicators of concern in order to build a bigger picture and predict possible adverse outcomes, will distort consent principles which should only be breached in exceptional cases and where there is risk of serious harm.

Thirdly, how might they impact on the relationships between children, families and social care professionals? Predictive technologies may actually dilute attention to the immediate needs of children. During its piloting of the Information Sharing Index, Telford and Wrekin removed a facility for practitioners to use flags of concern. For some practitioners, it seemed that their ability to mark-up a potential concern was making it less likely that they would themselves take action to meet the child's need. Similarly, Lewisham's use of RYOGENS revealed instances where practitioners' participation in a 'pooling' system actually diluted their sense of professional responsibility. Information was loaded without sufficient professional analysis, in the

expectation that other professionals using the system would undertake that analysis and initiate the appropriate intervention.

### **Parents with High Support Needs**

As set out earlier in this paper, however, the OCC is particularly concerned about the needs of families where parents have significant mental health problems which impact on their ability to care for their children, and/or alcohol misuse problems and families where there is domestic violence. A very high proportion of children who are Looked After by Local Authorities are in care as a direct result of at least one of these problems. It is estimated that between 50% and 90% of families on child care caseloads have a parent affected by mental health problems of some sort (some of whom may also have addiction problems).

### **'Think Parent, Think Child'**

There is evidence of a lack of joining-up between adult and children's services. This is not surprising given the focus on the client by practitioners who are trained to deal with one particular client group and to deal with their particular needs. But there is a pressing need for adults and children's practitioners to work together to address the problem, and to do so in such a way as to avoid stigmatising parents or risk deterring them from service use for fear of losing their children. The precise numbers affected are not known but given the figures that we do know of those affected by at least one of these problems, it can be seen that the percentage of children affected must be significant and these are clearly the children on whom our efforts must be focused. The following addresses these groups of parents in more detail.

### **Parents with mental health problems**

Between one in four and one in five adults will experience a mental illness during their lifetime. At the time of their illness, at least a quarter to a half of these will be parents. Their children have an increased rate of mental health problems, indicating a strong link between adult and child mental health. Parental mental illness is known to have an adverse effect on child mental health and development, while child psychological and psychiatric disorders and the stress of parenting are known to impinge on adult mental health. Furthermore, the mental health of children is a strong predictor of their mental health in adulthood.

In addition:

- Between 50% and 90% of families on child care caseloads have a parent affected by mental ill health
- Those who are most likely to need support and services are also those who are least likely to access them
- Gender, race, mental illness, parenthood, each carry the double or triple jeopardy of discrimination
- Women are afraid to come forward for help, particularly black women

- 80% black women with children in care are referred for MH, compared to 20% of white mothers
- Children and young people caring for a parent are the group most likely NOT to be offered a carer's assessment.
- There are as many as 17000 young carers in the UK; at least 30% of young carers are caring for a parent with mental health difficulties
- A quarter of all young carers report missing school
- Young carers are three times more likely to experience mental health problems themselves.

### **Parents with drugs misuse problems**

It is estimated that there are between 200,000 and 300,000 children in England and Wales where one or both parents have serious drug problems<sup>14</sup>. This represents about 2-3% of children under the age of 16 and accounts for a high proportion of those admitted to care. The consequences of parental drugs use for the child are diverse and serious, and there has, rightly, been a considerable focus in policy terms on addressing this issue with some good practice in local authorities/PCTs/mental health trusts who have made this a high priority.

### **Parents with alcohol misuse problem**

There is a body of research showing that children are adversely affected by parents who misuse alcohol. There has been less of a focus on this in policy terms, perhaps because there is less of a stigma associated with alcohol use and such use is legal. However, the consequences for children can be as devastating and it is estimated that there are 800,000 children in this situation. There is a strong association between alcohol misuse and domestic violence.

### **Domestic violence**

Domestic violence is common and 20% of women in England and Wales say they have been physically assaulted by a partner at some point<sup>15</sup>. Domestic violence has a massive impact on every aspect of a child's life and behaviour. In the short term, children may be fearful, withdrawn, anxious, aggressive and confused and experience difficulties at school. Longer term effects include lack of self-confidence and social skills, violent behaviour, depression and difficulties in forming relationships. Disrupted schooling can mean that they fail to reach their potential while others leave home early to escape the violence. The following statistics reveal the extent to which domestic violence permeates some children's lives:

- 30% of cases of domestic violence start during pregnancy<sup>16</sup>
- 52% of child protection cases involve domestic violence.<sup>17</sup>

<sup>14</sup> Hidden Harm report, Advisory Council on the Misuse of Drugs, date?

<sup>15</sup> Home Office (2001) British Crime Survey, England and Wales

<sup>16</sup> McWilliams, M & McKiernan J (1993) Bringing it out into the open.

<sup>17</sup> Farmer E & Own M (1995) Child protection policies: private risks and public remedies.

- 90% of domestic violence incidents occur while the child is in the same or next room.<sup>18</sup>
- 70% of children living in UK refuges have been abused by their father.<sup>19</sup>

Insufficient attention has until recently been paid to domestic violence as a child protection issue. Work is in hand at national level to address domestic violence and child protection issues together. Increased capacity will undoubtedly be needed to ensure that this is taken seriously at every level in all children's trusts.

The OCC would like to see existing Government programmes, for example, Sure Start, Children's Centres and CAMHS, integrate domestic violence into their core business and address children's need for support and protection. To achieve this, there is a need for additional specialist training, protocols and guidance which is regularly monitored and reviewed. This approach is dependent on the availability of local specialist domestic violence crisis and support services for children and young people. Similarly, services that advocate on behalf of children and young people and those that represent children and young people's voices (e.g. CAF/CASS) need to be fully aware of the impact of domestic violence on children and young people. This will ensure that their views are accurately represented in matters concerning them (e.g. child contact proceedings and arrangements).

We would like to see further investment in specialist domestic violence support services for children and young people based on a local assessment of need. In particular, there is a need to ensure children can access crisis intervention and longer-term ongoing support. There is an urgent need for a national funding framework for children's support in refuges, for support groups and services for children living with domestic violence and longer-term work in schools with all children.

### **Focus on Anti-Social Behaviour**

We are concerned that the dominance of the Respect agenda and the current focus on anti-social behaviour is taking attention away from recognising the complex needs of the parents mentioned above along with other families living in extreme poverty and facing severe social exclusion. The Government has invested a significant amount of time and resources on the anti-social behaviour agenda. We welcome the government's recent Social Exclusion Action Plan. The OCC believes that if properly resourced, these proposals, along with a network of family and parenting support services, discussed in the prevention section of this paper, would be a much more effective approach than the punitive and blaming approach that emerges from the Respect and anti-social behaviour agendas.

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<sup>18</sup> Hughes M (1992) 'Impact of spouse abuse on children of battered women', Violence Update, 1 August, pp9-11

<sup>19</sup> Bowker L et al, (1998) Domestic Violence Factsheet: children, Women's Aid Federation of England

## Engagement and Involvement

We strongly believe that more effort needs to be made to understand the values and life experiences of families and children entrenched in social exclusion and to positively engage with them and involve them in identifying what would help them the most. We believe that positive outcomes will be achieved by working with these families to seek solutions.

## Implications for the CSR

Much progress has already been made in addressing the needs of this important group of children and young people and much of the *Every Child Matters* programme is aimed at helping to identify such children early on, to provide a comprehensive assessment and to provide evidence-based interventions. There are, however, some risks as the programme develops which need to be addressed and mitigated:

- There is a risk that the perceived need to address anti-social behaviour dominates this agenda, since there will inevitably be some overlap between 'high harm' families where there are problems with drugs, for example, and those whose behaviour is seen as anti-social. Whilst acknowledging that anti-social behaviour is a problem that needs to be tackled, it would be unfortunate if this work stream focused on anti-social behaviour at the expense of the needs of what the National Service Framework for Children, Young People and Maternity Services referred to as 'Children in Special Circumstances'.
- There is a risk that in concentrating much of our efforts at early identification, we downplay the importance of prevention and tackling the root causes of social exclusion. The worrying trend in drugs misuse, for example, must be addressed through tougher measures to stop the supply. Further restrictions on the advertising of alcohol aimed at young people are also needed.
- There is a real risk of stigmatisation or labelling if predictions tools are used to assess those at high risk particularly if, as suggested in the Social Exclusion Action Plan, they are based on criteria such as teenage pregnancy or children who are or have been in care. It must be remembered that some children do well despite the most adverse of consequences whereas some others who appear to have no such risk factors fall off the rails.
- There is also a risk that moving towards what some critics perceive as 'nanny statism' will lead to the disempowerment of parents. The huge investment in child care facilities has undoubtedly made it easier for women to take up paid employment. However, what parents need is support as required at all stages of their child's life and to feel free to ask for support without being subject to sanctions or punitive measures.

- There is also a high risk of unnecessary intervention if services are delivered aimed at preventing families from becoming high risk. Given that the threshold for intervention by social care services appears to be too high currently, with many families in need not receiving services and considerable variation in provision of services<sup>20</sup>, this could make the situation worse and exacerbate inequities.
- Children's trust arrangements, intended to promote cross-agency and partnership working and to put the child's needs at the centre, could paradoxically place a new and unhelpful barrier between adults and children's services. Not only will this be unhelpful for transitions between those services, the above evidence shows that adults and children's services need to work far more closely together to ensure that the needs of children are given much higher priority in adult services. There is a need for improved joint working across children's social care and mental health services and adult mental health services, which needs to be reflected in joint protocols and shared training.

#### **What the OCC would like to see**

The OCC would like to see greater emphasis on the particular issues set out above. In particular, a specific PSA target should be included and reflected in resource allocations which address the need for better joining-up between adult and children's services to address the needs of parents with problems that affect their ability to parent.

Existing services could be asked to identify their adult clients who are also parents and to offer additional support as set out in the National Service Framework for Children, Standard 2. This should be done in such a way as to avoid the risk of stigmatisation. It may also be a more cost-effective measure compared to the cost of early intervention for all, and could be achieved through the workforce development programme.

Consideration should be given to putting more emphasis on assessments which are family-centred. The majority of those in current use, such as the Common Assessment Framework for children or the CPA for adults with mental health problems are focused on *either* the adult *or* the child; they may therefore not recognise the importance of the interaction between different family members.

Further research is needed to help us to understand more about resilience and what it is that enables young people who do succeed in difficult circumstances to do so: "*More effort has gone into the damage children suffer as a result of poor parenting than has been put into studying those who overcome the disadvantages of their upbringing*" (Booth and Booth 1997)

<sup>20</sup> The second Joint Inspectors' Report on Arrangements to Safeguard Children, July 2005

There could be greater promotion and dissemination of the importance of early attachment theory in adult services (maternity and mental health), and in early years and extended schools sector (e.g. Crittenden's research). This may be within the remit of the proposed new Centre for Excellence in Children's and Family Services, though could equally well be tackled by existing organisations such as SCIE.

More comprehensive data are needed on the level of need and epidemiology – to determine how many children are affected by the problems referred to here. This would enable us to get a better idea of the scale and the resource implications of early intervention in families facing these problems.

Forecasting of future need is also needed to enable children's trusts to plan more effectively based on the trends in drugs and alcohol use, for example.

## **Annexe 1: Consultation with NAS – Parents, Children and Young People**

30 August 2006 – 1 London Bridge

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The treasury is undertaking a comprehensive spending review for the joint Policy Review on Children and Young People for 2007. One of the key themes of this review is disabled children and youth services generally, so as to better improve outcomes for children, young people and their families.

The treasury asked the Children's Commissioner to speak with parents, children and young people on their views on how services for disabled children are provided to address:

- How both specialist and universal services can be improved.
- Ensure appropriate support is in place for disabled children during the school years and as they make their transition to adulthood
- Childcare services, particularly in the early years, to enable children's development and support parents

A session was held with children and young people who have been diagnosed with Autism or Aspergers on 30 August 2006 as part of the launch of the National Autistic Society's 'Make School Make Sense' report. The sessions were moderated by Sheila Moorcroft, who is an independent consultant, and were aided by the Children's Commissioner for England, Professor Sir Albert Aynsley-Green. Ms Moorcroft had issued the children with questions to think about prior to the event, as below. The children were allocated into two groups based on their experiences, with Group A predominantly secondary aged young people, and Group B consisting of majority primary aged children and one girl aged fifteen.

The children were asked the following questions:

- What is something good about school<sup>21</sup>
- Problems they have had with school
- Change for the future and what would improve their lives.

Notes were taken from the event and where possible, their views have been quoted verbatim in italics.

A separate session was held later for parents, carers and children addressing the specific questions submitted by Treasury for the Comprehensive Spending Review.

### **Group A**

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<sup>21</sup> School, in this environment, may be read to cover service provision generally, including education, social services, and health services, as children and young people's concerns focused on how to get into school, how to feel supported at school, and what other services enabled their school placement to be successful. Some children were being educated at home for a variety of reasons.

**Children in group A were invited to contribute to the group positive experiences about their schooling. Three of the 7 present were currently awaiting placements following the breakdown of their last school place. Children were encouraged to be positive, however, you will note that many positive experiences were accompanied by a negative experience of service provision.**

*I like one to one contact with my teacher...I really liked the teacher he was like a friend...but now he's gone and I don't know what will happen.*

*I prefer to be at school than being at home, I need to do something. School isn't the same everyday. Holidays are hard to organise any friends to do something...*

*I've managed to get into a college which caters to my needs (a teenager with Aspergers Syndrome) but it seems that there isn't going to be other places for people with Aspergers.*

*I have on-line friends (a home-schooled child with Autism) but I don't know them in reality.*

**The children were then asked to describe their negative experiences at school. Many in the group shared highly personal stories of bullying and depression, brought on by their experiences at school where they felt unsupported. They were asked to comment, where possible, on what would have made their experience more positive.**

*I can make friends with adults, but people my age...don't really talk to me...I sometimes tell them about Autism...but they talk about their friends and stuff which I can't relate to. I like to talk about politics and stuff and it would be good if we had a group set-up at school.*

*I started to feel depressed at primary school and controlled it with eating chocolate...which did the trick for a while...but at secondary school it became much worse and I was on anti-depressants and felt suicidal. No teacher was there with specialist knowledge...the SEN teacher told me it was my fault I had ASD<sup>22</sup>...there were no trained ASD teachers. I was signed off by the psychiatrist in Year 11 as I couldn't cope anymore – my GCSEs are out the window...*

Reflecting on their experience with other young people at school, a child stated, 'they don't invite me anywhere'.

*Teachers should have more knowledge, to pick out who might have Aspergers [teenager diagnosed at 12]. Even with the most basic knowledge I would have stuck out as someone with Aspergers. The kids were fine...it was the teachers that were bullies...from the first day it was a living hell...that was the first time I felt suicidal...after three weeks my parents pulled me out [of*

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<sup>22</sup> ASD - Aspergers Syndrome Disorder

secondary school] *that when the OCD<sup>23</sup> started. Mummy tried to do home schooling but it didn't work out entirely ok, years seven and eight were out...then I got into a special school in Year 8, they used to force me to do things...I went to another two schools but one I had to get on the bus at 7.30am to get there for 9.15...there's not enough special schools.*

*I was lucky because I had my two older sisters and brother...but my Year 8 support worker left out of the blue and I didn't have anyone to support me. I was handling it OK at school, but it took a lot to keep going and I'd blow up at home and it took a long time to get someone [a support worker] else.*

**The children and young people were then asked to suggest one thing they would like to change to make theirs and other's lives better.**

*The National Autistic Society have nailed it on the head with their three points – if those three things were properly implemented most of the problems would be solved.<sup>24</sup>*

*When it comes to sixth form college, they were telling me all things that I would get, but they didn't live up to my expectations...they need to do what they say they will...*

*More telling teachers about Aspergers so they know and they can spot people, and more support and special schools.*

*I've got loads of support and I did quite well in my GCSEs and I want other people to get the same chances.*

A parent added, *'Inclusion does work if the money is put into it'.*

## **Group B**

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**Group B were asked the same questions as group A. These children and young people were younger, and/or were less able to verbalise their situation. The format was as before with children first being asked to describe positive aspects of school and life.**

*I like my lunch...*

*I like playtime, chasing friends, I like literacy and reading, I like the puppets [acting out a scene from a play] but it was a bit embarrassing*

*Can do everything in the same place.*

*Not a lot...*

*Playtime! I love football.*

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<sup>23</sup> OCD – Obsessive Compulsive Disorder

<sup>24</sup> From the National Autism Society report, 'Make School Make Sense'

*Home time...and PE because I get to stay behind and work on my website.*

**The children were then asked to comment on negative experiences**

*Lonely...no-one will play with me.*

*People make fun of me – call me names and stuff [so] I kick out...*

*I was out of school for two years because the school didn't keep me. The problem was the other children, I didn't get on with them and they didn't get on with me and things went from there...teasing and physical trying to hurt each other. I felt teachers didn't do much I wanted them to stop them either they couldn't or they wouldn't – I think they couldn't. My new school is much better.*

*I haven't had many pupils in my class at my level [academically] which makes it a struggle. I've had a couple who were as clever as me and he was older, so he moved up to secondary, but there was really only two who were on my level. (A child attending a special school)*

*Sometimes I've been bullied and they bully me for no reasons, hit or kick or tease me and I feel angry and chase them*

*I don't like Monday, Tuesday and Wednesday because of Mrs B \_\_\_\_\_ [teaching assistant] I'm not allowed anyone else, no alternative. I hide under boxes to avoid her.*

**A number of parent's in this group spoke of their children's experiences on their behalf. Their views are represented below.**

*[You need to] make people aware of the nature of the difficulty our children face. The schools wants to help but don't understand the person who helps has to 'match'...I'm a teacher myself and we have a 'special needs' section who have no idea so they come to speak to me as the 'parent'.*

*There is a gap between policy and practice, fundamental lack of accountability for these children, and no-one is holding them [service providers, LEA etc] to account. And if your children doesn't have a statement there is no access to legal aid and there is no-one to hold to account. Pupil referral units become dumping grounds...*

*If they haven't got the budget – they should say so...*

*Inspections don't highlight [problems] at present – the voice of children and parents need to be heard.*

*Provision in the mainstream that caters for more able children, [i.e.: Aspergers] not just straight into mainstream. He [indicating son] had very challenging behaviours and nobody could have learned in that environment.*

[A Parent calling for additional support in mainstream for more able children with autism]

*[It was] written into the statement to have extra support over lunch, 1 hour, but they didn't have the funds to provide the support. LEA gave the funds to provide the support but it wasn't passed on...I made a complaint but it wasn't worth the energy with only 2 months left of the school term, and the Head Teacher had left...*

## **Parents and Carers**

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**Parents and some children and young people later convened for a focus group on the questions provided by Treasury. In the time available we were able to cover the questions that follow. Where presented verbatim, the text is presented in italics. The prefix [P] shows this is the voice of a parent, whilst [CYP] refers to opinions from children and young people.**

### **What are your experiences of the transitions between primary to secondary education, and beyond?**

Parents agreed that visiting the school, with increasing regularity as the term approached, was the most effective way of preparing a child or young person for a new school placement. However, only one parent had experience of this being part of the established school routine, whilst other parents stated they had experienced resistance when they had tried to visit the school to familiarise their child. This should occur in both mainstream and special schools. [P]

Parents felt that post-19 there was no provision. The comment was made, 'you either dematerialise or you 'cure yourself'. Children and young people only have a statement whilst they stay in school, and yet in some areas special schools always end at 16 – therefore parents felt they had lost all the entitlement they had gained. The emphasis was support needed to be continuing, and not cancelled because the young person had reached 18 or left school. [P]

*There needs to be some means of exercising compulsion on the local authority to provide the same kinds of services provided through a statement in other educational settings, i.e.: college. [P]*

*The experience of primary and secondary is very different, in primary school it is one class, the same faces, in secondary there are lots of different pupils and it is hard to get to know people. [P]*

*There is a lot of change and you can't form relationships. [CYP]*

*A child at primary school might do well and then be expected to perform to the same level at secondary, but the issues are not the same. [P]*

*There are lots of sensory problems at secondary school, there is no quiet space, and even though I had a 'red card' to show if I felt I needed to leave the class, it only made me feel more different. [CYP]*

**How do health, education and social care services work together? Have they seen evidence of these elements working together?**

*It gets to a crisis point before help comes in – Aspergers people don't 'fit' services as they assessed on an intellectual cognitive basis. Parents do the 'stitching' – when there's a problem parents sort it out [P]*

*Out of borough placements and the requirement to use services between boroughs such as Connexions don't work [P] [CYP]*

*Connexions personal advisor a misnomer, neither personal nor advising... [P]*

**What works?**

All parents agreed that when they were treated with respect, both for themselves and their children, that services were effective. This required their views to be considered equally alongside those of the professional, recognising their unique insight to their own situation as parents and children and young people. [ALL]

Holiday care can be fantastic – one teenage girl commented she really enjoyed a two week break – but it was a question of finding the right break for the child. [A child who had previously found holiday breaks unsuitable to her needs]

**For parents and carers who have required additional mental health services – was there adequate provision and referral to appropriate CAMHS services**

All stated there was no evidence of adequate provision to appropriate mental health services, and further, mental health services appeared incapable of directing children and their parent's to appropriate services.

**What service could have been provided from the outset to assist parent's/CYP more effectively?**

*Invest early and with the right level of support to go on and achieve, especially if the government is serious about getting people of incapacity benefit. [P]*