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Supporting families affected by autism

PACE response to Strategy Unit Disability Project Analytical Report August 2004

About PACE

PACE is a national charity established in 1998 to:

- raise awareness of the distinct needs of children with autism, and;
- work in partnership with central and local government to build services to meet those needs.

PACE has participated in five DfES working parties and the lay group to the Medical Research Council review of autism research. PACE helped establish the All-Party Parliamentary Group on Autism (APPGA) and is a member of the APPGA advisory group. We have a supporter database of over 1,500 families affected by autism, and have advised hundreds of parents across the UK who are working locally to improve services for children with autism.

Summary Response

PACE commends the Strategy Unit on producing such a detailed analysis of the current situation facing disabled people in the UK. While PACE is glad to see specific reference to autism within the report, our experience is that broad disability initiatives rarely demonstrate an understanding of how the autism-specific issues highlighted above can best be addressed. Given that the report is focused on improving the 'life chances' of disabled people, the section on Early Years is of critical importance, and this, along with the theme of early intervention, is where PACE will focus our comments. Our suggested policy recommendations are primarily given towards the end of this response, under 'Early Years Comments', 'Common Themes' and 'Conclusion'.

PACE believes that autism can justifiably be described as a 'special case' within the disability field because of:

- *The (rising) number of children it affects*

The National Autistic Society estimates that 120,000 children in the UK have some form of autism. The Medical Research Council review of autism research reached a consensus prevalence rate of 1 in 166 children under 8 – which would mean that 90,000 children are affected in the UK if extrapolated to the total population of children. Yet as recently as the 1990s, autism was still considered a rare disorder, and this is reflected by lack of any strategic planning framework for autism in many local authorities.

- *The complex needs with which the majority of these children present*
- Many children with autism present with complex co-morbidities, including epilepsy and bowel disorders. Even without these complex health needs, the fundamental social and communication impairments created by autism are likely to require intervention from a wide range of agencies.

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- *The requirement for specialist interventions to give the best chance of improved outcomes*

Children with autism learn and develop differently from other children. Although the relative efficacy of specific autism interventions generates a great deal of controversy, the expert consensus is that professionals need specialist training and an understanding of autism-specific methodologies to provide effective support to children with autism.

- *The lack of knowledge about autism amongst professionals*

72% of schools are dissatisfied with the extent of their teachers' training in autism; only one-fifth of teachers currently working with a child with autism have had any autism specific training.¹ This skill shortage hinders the potential for children with autism to be successfully included in mainstream settings, including nurseries, schools and after-school clubs, which heightens the social exclusion often experienced by their families.

- *The growing gap between need and availability of specialist provision*

PACE does not wish to engage in the sterile debate between advocates of total inclusion and those who believe that all children with SEN or disabilities should be educated in segregated settings. We believe strongly that a spectrum of provision is needed in each local area to accommodate parental wishes and the unique needs of every child. However, despite the fact that the number of specialist places for children with autism more than doubled between 1996 and 2002, rising numbers meant that the gap between supply and potential demand actually increased by 14% in this period.² Because of rising numbers being diagnosed, a push towards greater mainstreaming of children with autism is not incompatible with the case for greater specialist provision as well. Without this, increasing numbers of children with autism will be unable to access specialist interventions that may actively increase their chances of meaningful inclusion in society.

As the primary aim of the project is to assess the extent to which disabled people are experiencing adverse economic and social outcomes, PACE would like to reinforce the headline message in the sole cost benefit analysis of autism in the UK:

*The greatest costs are for living support (70%) and day activities (14%); much less is spent on education (7%). **Evidence suggests that even moderate increases in educational provision could potentially result in major savings in later living costs** (our emphasis).³*

Our key barriers

¹ Barnard, J et. al. (2002) Autism in Schools: Crisis or Challenge?, NAS: London

² Jones, G (2002) Educational Provision for Children with Autism and Asperger Syndrome: Meeting Their Needs, David Fulton Publishers: London)

³ Knapp, M. & Jarbrink, K. (2001) The Cost of Autistic Spectrum Disorder, Mental Health Foundation Updates, 1, 17

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PACE concurs with the report in the view that society has a responsibility to remove disabling barriers and to meet additional needs of people with impairments. However, both the disabling barriers affecting people with autism, and their additional needs, are subtle and profound – for instance, a flickering light or the proximity of others may create uncontrollable levels of stress for a person with autism who has hypersensitivity to certain stimuli.

In PACE's experience, the key barriers to improved life chances for children with autism include:

- **Segmented funding streams** – as in the case of a grandmother told that there was no money to pay her to have short breaks from caring, but that funding was available for an unwanted residential special school placement at vastly greater cost
- **Disincentives to investment in intensive early intervention** – which has been shown to generate the best outcomes for children with autism, but where potential savings will be made by a different team or department from that making the initial investment
- **'Cheapness' of long-term exclusion** – the failure of services to meet the needs of young adults with autism means that the most likely form of accommodation for adults with autism is the family home (49% in an NAS survey⁴). This means that family carers end up picking up the tab for their long-term care, and the cost of this is not reflected in existing benefit levels.
- **Rising numbers and costs** place 'the system' under enormous pressure. Evidence shortly to be published by the Council for Disabled Children shows that eligibility criteria for services are being manipulated to exclude children with high-functioning autism, while there are simply no services for those with autism and a learning disability who should be eligible for support.
- **Underskilling and underplanning in public agencies** exacerbates the shortage of appropriate provision, and this is not being addressed strategically, for instance through ensuring a minimum level of competency across the teaching profession via initial teacher training.
- **The continuing marginalization of parents**, who represent an untapped resource of expertise, skills and enthusiasm, as their relationship with public agencies is almost always adversarial. In education, the growing conflict between parents and LEAs is evidenced

⁴ Barnard, J. et. al. (2001), Ignored or Ineligible?, NAS: London

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by SENDIST statistics; between 2001-2 and 2002-3, the number of Tribunal appeals related to autism increased by 44%, from 490 to 675.⁵

Unpacking some concepts...

The report refers to many concepts and ideas that are current in the disability movement, but which may take on a different meaning for children with autism. The first of these is **inclusion**, which by necessity must have a meaning for a person with a social and communication disorder which is different from that for someone with a physical or sensory impairment. Many people with autism do not want to be forced to interact with others on a regular basis, and children with autism placed in mainstream classrooms without support are often the victims of bullying and teasing resulting from their social naivety. "Common sense" notions that young people primarily want to be with their peers in a straightforward way simply do not apply for most people with autism. PACE supports inclusion when it involves individuals and organizations adapting their attitudes and behaviours to the needs of children with autism, and where specialist support is available to ensure that children with autism continue to learn and develop and that their differences are treated with respect by others.

A term used frequently in the report is **prevention**, which perhaps reflects the policy direction to reduce dependency amongst those who develop disabilities in later life. Autism cannot be prevented, nor can it be cured. However, the most disabling aspects of the impairments associated with autism can be ameliorated, and programmes of evidence-based intensive early intervention are most likely to achieve this goal.

Accessibility is a major issue for children with autism, both in terms of social interaction but also in relation to the built environment. The use of clear signage, verbal announcements and muted colour schemes in public places can make interacting with the social world less traumatic for some children on the autistic spectrum. Indeed, this issue of sensory sensitivity highlights the problematic concept of **severity** in relation to autism, as children with very high IQs may have severe and profound social and communication impairments, and will need sustained and intensive support to achieve their full potential.

Early Years comments

PACE welcomes the fact that the report devotes an entire section to the current provision of early support for disabled children. PACE would like to emphasise that generalist interventions such as Portage and parent support programmes such as EarlyBird, while undoubtedly of benefit, are no substitute for specialist, intensive early intervention for children with autism, as

⁵ SENDIST Annual Report 2003

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recommended by National Autism Plan for Children (NAP-C)⁶. Unfortunately, although NAP-C is intended to be a practical local area template for autism services in the early years, even those local authorities who are aware of its existence appear to be treating it as an aspirational wish-list, as current levels of resourcing do not permit its implementation.

While the report rightly identifies many of the structural and organizational barriers to improved provision for children with autism, it does not address who holds responsibility for strategic planning. Although PACE hopes that the integration of unified children's services departments and Children's Trusts will improve multi-agency planning processes, the issue of where autism 'fits' will still remain. In different local areas, autism is considered to be a learning disability, a mental illness or, in particularly 'clued-up' authorities, a developmental disorder with a discrete set of service needs. Senior managers must be encouraged to take a decision as to who will lead in each local area on planning autism provision, and that person or team must be accountable to, and willing to engage with, local parents. The particular needs of children with autism mean that, in PACE's view, the creation of a single definition of disabled children and generic pan-disability minimum standards (p74) would do little to improve services for the families we support.

The challenge for those working with disabled children in general, and children with autism in particular, is to ensure that the needs of these children are not 'swamped' by the dominant mainstream agendas of child protection and school standards. In our view, this can only be ensured if services for children with autism are prioritized in spending agreements and monitored through targets and inspections. PACE hopes that the forthcoming Children's National Service Framework, which will contain an important autism exemplar care pathway, will be sufficiently resourced to ensure successful implementation. If it is not, then an addition to the list of potential consequences 'If we get it wrong...' (p77) will be increased public expenditure over the lifetime of a person with autism.

Common themes

PACE fully supports the principle of the common themes set out in the report that will deliver improved life chances for disabled people, but we have some concerns as to their likely practical impact. For instance, putting **disabled people at the heart of services** is a laudable intention, but how will this be delivered for people with social and communication difficulties? It would be perverse if local managers used this objective as an excuse to place the

⁶ A report published by the National Autistic Society on behalf of the Royal Colleges of Paediatrics and Child Health and Psychiatry, with the support of the All-Party Parliamentary Group on Autism – available at www.nas.org.uk

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burden of service improvement on disabled people. In this section, PACE has concerns about two of the assertions made in the report:

1. 'disabled people know more about what works for them'

It is a truth universally acknowledged in the autism field that no-one knows conclusively what works. The single outcome of this project that would be of most benefit to the life chances of people with autism would be a pan-governmental commitment to significant investment in evaluating outcomes from the range of autism-specific interventions in the 'market', and then ensuring that parents, and where possible children, have access to high-quality and accurate information about their relative efficacy. As the report itself states (p205):

A range of interventions aimed at improving the life chances of disabled people are available. The comparative value for money and cost-effectiveness of these interventions needs to be assessed before policy recommendations can be made.

As a first step, Government should take action to address the 'urgent need' for a large longitudinal data set that could be used to resolve many of the issues about the relative impact of different interventions, as identified by a recent DfES research report.⁷

2. 'impairment-specific advocacy tends to perpetuate the medical model'

In PACE's view, this statement in turn tends to perpetuate an essentialist view of 'disabled people', undermining the recognition in the introduction to the report (p16) that disabled people are a heterogeneous group. In fact, non-impairment-specific advocacy tends to exclude people with autism, as shown by NAS research amongst independent advocacy providers, which found only one example of a service that worked regularly with people with autism.⁸ This highlights the generic danger that children with autism and their families will fall off the radar of both mainstream and pan-disability initiatives, as meeting their needs proves too costly or too complex.

Within the remaining cross-cutting themes, PACE would emphasise again that the current mechanisms to prioritise funding for **early intervention** consistently provide insufficient incentive for public agencies to act. In terms of **cost-effectiveness**, we would highlight the importance of the concept of treating measures that enhance the life chances of children with autism as capital rather than revenue expenditure, particularly in the context of the current minimal levels of spending on 'prevention', with the Early Support programme as a notable exception. In the section on **joined-up working**, we

⁷ Papps, I. & Dyson, A. (2004), The Costs and Benefits of Earlier Identification and Effective Intervention, DfES: London

⁸ NAS (2003), Autism: The Demand for Advocacy, NAS: London

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feel it is important to note the massive impact of the current failings on parents and carers, who tend to be forced into the role of keyworkers for their children with autism. Indeed, PACE would like to see the needs of parents and carers, and the support they offer to the life chances of children with autism, more clearly emphasised throughout the report.

Conclusion

PACE agrees with the Strategy Unit's framework recommendation (p219) that disabled people need to be 'at the centre' of mainstream policy initiatives across Government. Yet being 'at the centre' has two very specific meanings for children with autism. Firstly, we have found that these children are often neglected as a hard-to-reach 'core', surrounded by children with other disabilities where solutions are simpler for service providers. Secondly, children with autism are at the centre of family networks which are put under extreme stress by the underprovision of basic services in many areas.

PACE would like the policy recommendations from the project to address three key questions:

- Does delivering decent services for children with autism require infinite budgets? Or could we 'pump-prime' provision, such as large-scale professional training programmes, to reap later savings?
- How can joined-up Government deliver a genuine co-ordination function, for instance ensuring that the autism research agenda delivers outputs that inform policy decisions, or requiring all agencies to collaborate on accurate and consistent data collection?
- Is there room in the debate between advocates of the medical and social models of disability for consideration of the structural barriers that impede the life chances of children with autism, for whom changes in attitudes, organizations and the environment alone will not be enough to deliver genuine inclusion?

Our final question would be - is there the political capital across Government to deliver real improvements in services for some of the most vulnerable and excluded children in this country, given that the cost is likely to outweigh the electoral benefit?

PACE is grateful to the Strategy Unit team for the opportunity to input into this project, and looks forward to seeing the policy recommendations contained within the final report, and where possible assisting in their implementation.

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