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Dear Chris

Consultation on Self-directed support: A National Strategy for Scotland

Action for Children Scotland welcomes the opportunity to respond to the consultation on *Self-directed support: A National Strategy for Scotland* ("the National Strategy"). Our response raises certain general issues around self-directed support, as well as addressing some of the specific questions raised by the consultation document. Action for Children Scotland's response draws upon our experience of providing support to children and young people with a disability, and to their families, at a number of our services, including the Gilmerton Road Project in Edinburgh, the Lisalanna project in Ayrshire, the Silverton Short Breaks Project in South Lanarkshire and the Tayavalla Family Support Project in Falkirk. For ease of reference we have used the same headings as the consultation document.

In summary the key issues Action for Children Scotland wishes to raise are:

- **We welcome the Scottish Government's commitment to develop and introduce the National Strategy;**
- **The National Strategy should contain a stronger focus on the support which voluntary sector organisations can provide;**
- **The Scottish Government should develop and progress a specific strategy to provide support to children and young people with a disability, and to their families;**
- **We are concerned that the focus on Personal Assistants could lead to the development of a two tier workforce;**
- **The interface between the National Strategy and key strategies relating to children and young people, such as GIRFEC and the Early Years and Early Intervention Strategy, should be clearly highlighted;**
- **Given the significant role which it is proposed Community Planning should play in the delivery of the National Strategy, it is essential that Community Planning Partners do more to engage the voluntary sector in this process; and**
- **We welcome the emphasis placed on the need to make resources available through self directed support to help young disabled people to make the transition to adulthood.**



General

Action for Children views personalised care as a means to give individuals more choice and control over the services they use, and to shape tailor-made services to help children and young people to achieve better outcomes. The values of personalisation have long underpinned our work across the UK, and we have consistently tailored our work to match local circumstances, in partnership with local authorities and other local agencies, children and young people, families and local communities. Action for Children Scotland, therefore, welcomes the Scottish Government's commitment to improve the level of choice available to individuals through the development and introduction of the National Strategy on self-directed support. We also welcome the long term approach being taken by the Scottish Government to the development and delivery of this strategy.

Action for Children Scotland is a member of Community Care Providers Scotland ("CCPS"). We share CCPS's concern that the National Strategy should place greater emphasis on the significant role which the voluntary sector can play in developing personalised approaches to care. In this respect, it is essential that the National Strategy, while confirming the services provided by Personal Assistants, highlights that individuals also have the right to contract directly with voluntary sector providers for support, or to have these services commissioned by their local authority.

We believe that the National Strategy should provide a clear statement on how self directed support will apply to children and young people with a disability, and to their families. In this respect, the National Strategy should, for example, give local authorities clear guidance on the need to ensure that monies received under the UK Government's Aiming High for Disabled Children strategy are used to transform disabled children's services, and on the role of self-directed support within this process. The interface between the National Strategy and other strategies relating to children and young people, such as GIRFEC and the Early Years and Early Intervention Strategy should also be clearly signposted. This will help to ensure that key agencies, including local authorities, NHS Health Boards and the voluntary sector, take a joined up, integrated approach to the provision of support to children and young people with a disability, and to their families.

Furthermore, Action for Children Scotland notes the Scottish Government's commitment to develop specific strategies to support individuals suffering from dementia, and to help carers. Against this background, we take the view that the Scottish Government should also develop and progress a specific strategy to support children and young people with a disability, and their families.

Why a strategy now?

Action for Children Scotland welcomes the National Strategy's emphasis upon the rights of people with a disability. We further welcome the priority being given by the Scottish Government to Independent Living, and note the vision developed by the Scottish Government working group. Action for Children Scotland believes that this vision should, in order to further strengthen the rights of disabled people, include a reference to "respect".

RECOMMENDATION 1: In 2010 the Scottish Government in conjunction with COSLA should review, and clarify the use of eligibility criteria for adults and older people as it applies to self-directed support.

Action for Children Scotland shares CCPS's concern that local authorities, faced by the need to make significant financial savings, will introduce tougher eligibility criteria. We are particularly concerned by the potential impact this could have on self directed support for children and young people with a disability, and their families. Action for Children Scotland shares CCPS's view that low level, early intervention can produce longer term savings to other budgets. We believe there is a risk that the introduction of tougher criteria could leave those with low level needs without support until a crises point is reached. Action for

Children Scotland, therefore, support CCPS's recommendation that the Scottish Government should have further discussions with a wide range of key stakeholders about eligibility criteria.

RECOMMENDATION 3: The Scottish Government should encourage community planning leads to support social work and other local authority departments and agencies to work together and combine their funding to achieve better outcomes for people who have personal and social support needs.

RECOMMENDATION 4: Community planning partners should consider pooled resources to support the development of local area co-ordination for all client groups.

Action for Children Scotland notes the significant role which it is envisaged Community Planning will play in the delivery of the National Strategy. We believe it is, therefore, essential that local authorities, Health Boards and other Community Planning Partners must take a more consistent approach to actively engaging the voluntary sector in the Community Planning process across Scotland. This will help to achieve better outcomes for individuals with personal and social support needs, and to ensure that local area co-ordination is improved for all groups. It will also make an important contribution to the economic analysis which is required to identify the level of investment necessary to achieve "the right balance between lower level and critical and substantial supports".

Employment and Education

Action for Children Scotland works closely with local authorities and other partners to improve young disabled people's access to work, and to opportunities in education and in training. Young disabled people face significant barriers which limit their access to these opportunities. These barriers include issues around benefits, and in particular the loss or reduction of some benefits where a young person is able, and would like to, work more than 16 hours. Other barriers include the lack of accessible transport, the limited availability of good augmentative communication methods, poor access to buildings for disabled people, and the lack of good toileting facilities. Careful thought should also be given to ways in which it can be made easier for young disabled people to work, study and mix with others, especially where communication barriers may exist. These are all areas demanding significant improvement, given the adverse impact they can have on young disabled people's efforts to access opportunities in education, training and in employment. Against this background, we welcome the emphasis in the National Strategy that self-directed support "should enable more people to access the education, training and support for work that they need to enable them to lead a full life".

RECOMMENDATION 7: Beginning in 2010, the Scottish Government, with others, should evaluate existing models of support provision to inform a more efficient, sustainable and joined up approach, at both local and national level, suitable for all citizens.

Action for Children Scotland recommends that the Scottish Government should as part of the evaluation process give consideration to the experience in England of personalisation. In March 2009, the UK Government announced that a small number of local authorities along with their primary care trust (PCT) partners had been invited to pilot *Aiming High for Disabled Children* individual budgets for families with disabled children. While offering individual budgets to the full range of eligible children and families, it was anticipated that each site would also have to identify a beneficiary group upon which they would focus. These groups were:

- children coming out of early support;
- young people in transition; and
- newcomers to the social care system

Previous individual budget projects in England have been well received by parents and young people, but have flagged up delivery issues. Families report that life is made easier through being able to talk directly to providers about when they want support, without having to have funding agreed first.

Providers have started to think about how they can support young people more flexibly, and there are a range of providers that can be approached.

Developing an individual plan can, however, be a time consuming process, and this is by no means a quick fix solution. It is important to ensure that families receive support from professionals who have a good knowledge of the personalisation agenda, and of the processes required for individual budgets. With changes in project leads and social work teams it has been a challenge to ensure that the families are well supported throughout the process.

Moreover, families with disabled children have complex lives. In England concerns have been raised that some families may feel that the management of individual budgets adds an extra level of complexity that has a negative effect on their ability to lead ordinary lives. This will be particularly true where individual budgets are not designed with the specific needs of disabled children and their families in mind, and if pilot schemes have not included disabled children and their families from the start.

Parents of disabled children want to take control of their lives. For many, this will mean having the option of individual budgets or personal health budgets, and helping to shape the services they receive through participation in parent forums. Others, however, will need the support of key workers or brokers to help them to navigate the system, and to ensure that co-ordinating services does not become a full time job.

In England, the Council for Disabled Children is co-ordinating a working group for the Association of Directors of Children's Services to look at the implications of personalisation on the planning of local services. In addition, work will need to be done to ensure that the voluntary sector is equipped to respond to the demands of personalisation. The Council for Disabled Children has put together a working group to look at the requirements of the voluntary sector in preparing themselves to respond to this new method of commissioning.

RECOMMENDATION 8: Beginning in 2010, the Scottish Government should work with COSLA in using economic analysis to identify the best strategies available to local authorities so that they can lead a shift towards self-directed support focussing on a shift to commissioning for individuals rather than for groups.

The proposed changes outlined in the National Strategy must ensure that "commissioned services still enable individuals to exercise choice and control over their support and achieve the best outcomes for individuals". We support CCPS's view that this will require further training for commissioners, and for other social work professionals.

RECOMMENDATION 9: In 2010 the Scottish Government and COSLA should gather and interpret information on the evaluation of resource allocation models and systems to see which approaches best deliver the outcomes for all groups and levels of need, and whether and how systems can provide the best possible outcomes for both younger adults and older people.

Action for Children Scotland shares CCPS's concern that the move towards self directed support must not be used by local authorities as an opportunity, or excuse, to cut social care costs without regard to outcomes. We, therefore, welcome this recommendation, which will help to identify the approaches that best deliver outcomes. Action for Children Scotland recommends that this evaluation of resources should include analysis of how local authorities have used the *Aiming High* monies to transform services for disabled children and their families.

RECOMMENDATION 10: By autumn 2010 the Scottish Government should meet with DWP officials to ensure that the self-directed support strategy and the benefits system funding streams, fit together in an appropriate and cost effective way, to the full advantage of those using self-directed support. An aim of this should be to seek a reduction in business processes around Charging Policy and SDS.

Action for Children Scotland welcomes this recommendation, given the need to ensure that the Scottish Government and DWP officials take a joined up approach to issues around the development of the National Strategy and the benefits system funding streams.

RECOMMENDATION 11: By December 2010, the Scottish Government should discuss with Education leads whether and how Disabled Students Allowance and other relevant funds in Further and special, and Higher education can be included in self-directed support packages.

We further welcome Recommendation No.11 which potentially could make an important contribution to improving the access of young people with a disability to Further and Special and Higher Education.

RECOMMENDATION 13: Building on recommendation 9 above, the Scottish Government in conjunction with COSLA should commission a Scotland-wide analysis of the rates offered for individual budgets and direct payments, and the costs for equivalent services provided by local authorities and the independent sector, with a view to assessing how these meet individual outcomes.

Action for Children Scotland welcomes the commitment in Recommendation No.13 that the Scottish Government and COSLA will commission an evaluation focusing on costs and outcomes.

RECOMMENDATION 14: The Scottish Government should consider with SPAEN and support organisations and PAs the need to develop a national organisation to support PAs.

RECOMMENDATION 15: The Scottish Government should consider the ways in which PAs can access training, how a direct payment can be used to provide training and the range of responsibilities placed on local authorities to ensure a sufficiently training PA workforce.

RECOMMENDATION 16: The Scottish Government should disseminate the findings of the research on the PA workforce commencing in 2010. Other organisations should assist in making it readily available thereafter to both potential employers and employees.

RECOMMENDATION 17: The Scottish Government will work with local authorities and support services to be able to assist employers to proactively to comply with employment law and best practice.

Action for Children Scotland shares CCPS's concern that the National Strategy, as currently drafted, focuses too heavily on the employment of PAs. We believe this strategy does not place sufficient emphasis upon the services available from the voluntary sector, or which can be commissioned through the local authority. We share CCPS's concern that this imbalance in the National Strategy could give rise to a two-tier workforce, given the tendency to pay the unregulated PAs lower rates, and to provide lower levels of training and supervision to the latter compared to voluntary sector and local authority staff. These factors underline the case for progressing CCPS's recommendation that further thought should be given to ways in which voluntary sector providers can provide support to individuals who commission services from PAs, and to PAs.

Furthermore, we believe that, given the unregulated status of PAs, it is essential that the National Strategy should be reinforced by a clear statement of care providers' safeguarding duties and responsibilities in relation to children and vulnerable adults.

RECOMMENDATION 18: In applying Scottish Government guidance on social care procurement, local authorities should take account of the values and principles of self-directed support, and in turn promote independent living.

We support CCPS' view that "a move to self-directed support represents an alternative to social care procurement, rather than being part of it", and suggest that Recommendation No.18 should be redrafted to reflect this.

RECOMMENDATION 19: During 2011, local authorities should work in partnership with providers to develop provider networks in each area. These networks should look at ways of supporting citizens to singly or collectively commission services.

Action for Children Scotland would welcome clarification of whether or not this recommendation refers to both PAs, and to organisations which provide care services.

SDS for Specific Groups

Action for Children Scotland welcomes the recognition in the National Strategy that: “Self-directed support may be particularly relevant to young people who require AAC support at the point of transition from child to adult services”. Action for Children Scotland is aware that a great deal of service provision focuses on the needs of children aged 5 to 18 but that, in many areas, the support for young disabled people during the transition from childhood to adulthood is minimal. We are further aware that the extensive support which many young disabled children receive throughout school generally reduces once they reach school leaving age. Indeed, apart from the provision of some short term respite care at 18, it is fair to say that young disabled people receive little, if any, support between the ages of 18 and 25. This significantly reduces the number of life opportunities available for young disabled people, and perpetuates many of the barriers which blight the latter’s adult life.

By way of illustration, it is worth reflecting on the experience of young disabled people who are encouraged to go straight from school, where they have considerable support and a social network, to colleges where they often have little support and feel isolated. Action for Children Scotland considers that the National Strategy should highlight that this transition needs to be better managed by key agencies, if we are to ensure that the experience of all young disabled people at college is both positive and rewarding. In this respect, we believe that the National Strategy should emphasise that resources should be made available through SDS to give young disabled people the necessary support to assist them make the transition from the relatively supportive environment of school to college.

Against this background, Action for Children Scotland considers it is vital that the Scottish Government, local authorities, the voluntary sector and other key agencies should do more to support young disabled people through their transition from childhood to adulthood. To support young people through this transition Action for Children Scotland also recommends that:

- disabled young people must be at the centre of the transition process;
- a key worker is essential to help navigate and support young people, and their families through the transition period;
- during transition young people should have access to an advocate;
- adult services must meet the needs of the young person as an individual;
- there must be continuity in the level of support if assessed need has not diminished; and
- disabled young people should be taught key life skills

Providing such support at this stage in the lives of young disabled people through SDS can help to assist the latter to cope with this transition. Furthermore, it will increase the level of opportunities available to young disabled people in areas such as education, employment and training, and their social lives. Reducing barriers in these areas will, in turn, help to promote the integration of young disabled people into society.

RECOMMENDATION 22: The Scottish Government should consult on the need for, and the provisions of, a Self-directed Support Bill by Spring 2010.

Action for Children Scotland welcomes this recommendation.

RECOMMENDATION 23: The Scottish Government and key stakeholders should work together to review and update the Community Care Outcomes Framework by summer 2011 in order to ensure that all client groups and forms of community care support are adequately represented in data collected for Local Outcome Agreements.

Action for Children Scotland welcomes this recommendation, and would be willing to work closely with the Scottish Government and other key stakeholders to review and update the Community Care Outcomes Framework.

RECOMMENDATION 26: Scrutiny bodies should devise a method to measure the incremental progress of the policy collaboration with individuals, carers and other interested parties and commence a scrutiny programme by 2012.

We share CCPS's concern over "the increasing anomaly between support that is provided within the regulatory framework by provider organisations, and support that is provided by PAs entirely outside that framework", and supports CCPS's recommendation that a specific strategy should be introduced to address these issues.

Please do not hesitate to contact me or Moira Luccock, Operational Director of Children's Services, on 0141-550-9010 if you require more information, or would like to discuss any of the issues we have raised further.

Yours sincerely



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