Which areas of preventative spending/ the preventative agenda would it be most useful for the Health and Sport Committee to investigate?

The Scottish Transitions Forum provides evidence and learning that explores transitions issues and solutions via the 7 Principles of Good Transitions (Download it from www.scottishtransitions.org.uk). The Forum consists of over 580 members. The Scottish Transitions Forum is aware that preventative spend in the area of transitions would be warmly welcomed by our multi-professional membership and parent and young people representatives across Scotland. We know that many young people with additional support needs find the transition to young adult life particularly challenging. These challenges are long standing and are exacerbated by:

- Organisational processes taking priority over individual needs
- Lack of support for carers and families
- Lack of resources
- Insufficient planning
- Unclear transitions pathways
- Limited options
- Lack of clarity about accountability

Transitions Defined
Transition is defined by the Scottish Transitions Forum (2016) as:

_The time when young people develop from children to young adults. This is not a single event, such as leaving school, but a growing up process that unfolds over several years that includes significant emotional, physical, intellectual and physiological changes. Over this period, children and young people will progressively assume greater autonomy in many different areas of their lives and will be required to adjust to different experiences, expectations, processes, places and routines. Transitions will also impact on the family or those who care for the child or young person._

Time and again members have come to realise that this point in time can best be supported by the impact of preventative spend similar in approach to the early years agenda. Many young people drop off the Health care track as they move into adult health and social care services. By providing preventive spend models to ensure young people are fully supported

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through this period would ensure that young people can be better fully supported to live an independent life and are still engaged with the processes and systems that support them. This means that they will be prevented from arriving in crisis to adult health and social care agencies later. This approach of investing to prevent later crisis spending would ensure an invest to save approach that has recently been proved in the research carried out by professor Tommy Mackay (to be published this year).

- **How can health boards and integrative authorities overcome the (financial and political) pressures that lead to reactive spending/ a focus on fulfilling only statutory duties and targets, to initiate and maintain preventative spend?**

  Self-directed support, early intervention and the Getting it Right for Every Child approach are step away from eligibility criteria in Children services there still exists the challenge of the transitions into adult services and a different system of eligibility. Access to proper housing, food and clothing, access to financial help to bring up young people and to take part in things are all rights that young people have (UNCRC articles 18, 26 and 27). However, Scottish Transitions Forum members are concerned about inequities and inconsistencies in the application of eligibility criteria across and between local authorities from child to adult services that prevent young people from accessing these rights.

  The inconsistencies in eligibility criteria and resources, can mean that many children and young people have significantly reduced access to services as they make the transition into adult life. Progress made whilst supported in children’s services may also be lost as they move into adult services due to lack of continued support. In addition, changes to welfare entitlements and complicated benefit reassessments often mean young adults with additional support needs are in a worse financial position than when they were children.

  The level of funding available for health and social care services is reducing as austerity measures are implemented. This has impacted on the eligibility criteria set by local authorities to determine who is eligible for funded support. In many authority areas funded support is provided only if individuals meet a threshold such as ‘substantial’ or ‘critical’ level of need. In some areas funds are limited to critical need only. This has resulted in 1 in 7 (20,000 people in Scotland) loosing funded support according to recent reports.

  Investment made in the early years may be lost as children move to adult life. As children, they may have received substantial packages which support their well-being and

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6 LDAS (2014) 20, 000 lose out: 1 in 7 lose social Care Due to Changing Eligibility. Learning Disability Alliance Scotland.

outcomes from social work services and specialist health provision, in addition to universal services like education. But as comparatively fewer resources are available to fund further education and adult health and social care the investment may reduce considerably and abruptly when they become an adult. This is particularly the case for people who do not meet eligibility criteria for funded adult services.

The challenging financial climate has led to some families falling into ‘at risk’ categories as they seek access to the funded services they require to maintain their basic needs.  

Young adults access to services is often based on assessments that describe the ‘worst-case scenario’. This can paint an incomplete picture of the young adult’s life and those who care for them. Outcome based approaches through self-directed support and the focus on the well-being of children and young people seek to remedy this situation. However, due to funding cuts professionals are aware that often only the most negative of situations are eligible for support when people move to adult services. This deficit model presents young adults as consumers of services, rather than contributors to society and is a barrier to them achieving their potential.

**More support should be available for those who do not meet eligibility criteria**

We recommend more support including those out with those provided by health and social care partnerships, need to be explored with young people in transition and their carers. Such a process will also help to create greater awareness of the need for community assets in assisting people to meet their outcomes outside of funded provision. Other measures include helping families to plan activities together and explore pooled budgets.

Supporting young people in identifying personal outcomes leads to increased choice and control over their lives. The Social Care (Self-directed Support) (Scotland) Act 2013 and other agendas, such as the Scottish Strategy for Autism, Keys to Life, Personalisation, Reshaping Care and the Scottish Transitions Forum evaluation report “What Next?” agree that there is often value in pursuing alternative supports to traditional services. Offering support to enable people to be more connected in their local communities helps to enhance both individual and community health and well-being.

In the absence of health and social care support, parents or carers often have to provide this support themselves as the young person becomes an adult. For some, this

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8 Contact a family (2012) Counting the costs: The financial Reality for Families with disabled children across the U.K.
means having to leave their employment when the young person they care for leaves school or college. The additional strain this puts on families can lead to crisis in the longer term. Aside from the impact this can have on the health and well-being of young people and families, the absence of support through an established transitions pathway may cost more in the longer term. Young people with additional support needs, in particular disabilities, at age 16 and 26 are less satisfied with their lives and have lower subjective well-being than non-disabled people of the same age. Many feel that they are not granted a right to be part of the community, and to have choices. The Government has acknowledged that only a minority of people with learning disabilities had a paid job, and that, where people were employed, they often worked for less than sixteen hours per week. Without some support, even a little to overcome these difficulties, many young people with additional support needs may fail to achieve their potential. There are services that help to find employment opportunities for example, Real Jobs, PAMIS - Future Choices, Project SEARCH, SHARE Scotland and Cornerstones Moving on Transitions Project, Skills Development Scotland and Opportunities for All. Opportunities for All work with young people up to age 19 (or 21 in exceptional circumstances) and Skills Development Scotland are there to support all young people. However, research has found these services come with their own eligibility criteria.

22 http://www.scld.org.uk/scld-projects/project-search
23 http://www.sharescotland.org.uk/Projects/m-o-transition-service.html
24 https://www.skillsdevelopmentscotland.co.uk
25 Scottish Government (2012) Opportunities for All: Supporting all young people to Participate in post-16 learning, training or work. HMSO. Edinburgh.
and ways of working, which might present barriers to access for young people with additional support needs.26.

Preventative spend is also hard to put in place due to the turnover of parliamentary and local political leaders. Due to this, it’s challenging to put in place the preventative spend model as it takes a while to progress through the system and savings gained from putting in this approach can be used in politics at later points to demonstrate effective policies that were put in place by earlier political leaders or removed altogether. It takes a while for the evidence of this approach to take shape and it is outside the current political timetable of three to four years.

This approach would also need increased investment over the short term as the two systems would have to run side by side to one another. There would be young people facing crisis but also you would need to roll out the preventative model at the same time.

- **How could spend that is deemed to be preventative be identified and tracked more effectively? What is required in terms of data, evidence and evaluation to test interventions for producing ‘best value for money’?**

A variety of approaches are created to help address this, including the use of post 16 tracking data collected by Skills Development Scotland, which includes a large number of information sources. Further work is being explored under the Autism Improvement programme and the Scottish Strategy for Autism, Keys to Life, Learning disability observatory and the new exploration of support needs data in the NHS27.

However, we recommend that more work should be done to establish a clearer picture of the numbers of young people with additional support needs who are receiving post school support, the outcomes they are achieving in different aspects of their lives and the levels of unmet need. Improved data collection is required, locally and nationally, to understand the level of demand and capacity of services and other stakeholders to meet this, and to inform and measure improvement of effective and sustainable change.

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The above has been taken from Scottish Government Attainment and Leaver Destinations Supplementary data available online. We have taken data from three reporting years. 2012/13 reported in 2014 and the years 2014/15 reported in 2016.

This shows that attainment of positive destinations has increased for all pupils by 1.6 percent. For children with additional support needs attainment has decreased overall by 1.3 percent. The data does not demonstrate a trend. It is a comparison of positive destinations across Scotland by SEEMiS category. This could indicate an area where investment in prevention would also impact whole life wellbeing.

Data hub

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28 Data can be found here: http://www.gov.scot/Topics/Statistics/Browse/School-Education/leavedestla/follleavedestat
The 16+ data hub is a secure online portal which allows a range of partners, including Skills Development Scotland, to input and access a combined database of information on individuals as provided for in the Education (Additional Support for Learning) (Scotland) Act 2004 with consent from those who ‘own’ the data and other legislative requirements.

This new approach to data gathering should help explore what the young people who have left school or college have gone on to and thus help provide a better overall picture of young people with additional support needs in Scotland.

The 16+ data hub reports help partners to provide targeted support to young people specifically those not in education, training or employment. The information includes details of all young people aged 16-24 who are:

- Receiving careers support
- Planning on leaving school
- Starting and withdrawing from college
- Receiving benefits.

The exchange of data allows reports to be extracted that are tailored to partners’ specific areas. Regular uploading of data by partners ensures the reports are up to date.

The participation measure is being developed by Skills Development Scotland, which will inform the Scottish Government’s National Performance Indicator, ‘to increase the proportion of young people in learning, training and work’ It will support the overall ambitions of Opportunities for All and allow an assessment of the impact and support provided by partner agencies on the 16-19 age group. This will help young people access the support, learning and training they need as they move toward employment.29

Not all young people with additional support needs are able to achieve open employment. This means they may rely on services provided for by health and social care. However, some of these young people might not be eligible for this support. These young people should still have the opportunity to be supported to engage with their community in ways that allow them to be included and valued. Community advocacy, active citizenship and engagement projects can help people achieve this. These approaches are echoed in the Creating a Fairer Scotland: A New Future for Employability Support Consultation Response Report.30

For more information, go to www.sds.co.uk/information-sharing

Eligibility background

There is an expectation that young people who meet a certain level of criteria should receive a funded service from integrated care services when they move onto young adult life. This is subject to an assessment which acts as a gatekeeper. Everyone is entitled to an assessment (s.22, and S.23 of the Children’s Act and S.12 of the Social work Scotland Act).

The impact of eligibility is explained fully in the work of the Children’s Commissioner’s report “it all comes down to Money. 31” This theme is also picked up in the work of Colin Salzberg 32 who discusses the complicated arena of equitable provision of services. These themes are also picked up in the Mapping Project carried out by Simon Jacquet on Behalf of ARC Scotland and STF and the Principles of Good Transition.

One of the difficulties we have in understanding those who have fallen through the gaps in service provision between children and adult services during transition is the area of unmet need. Unmet need isn’t tracked across Scotland. Services such as health and Local authority numbers only track those they have provided a service to. Why this can be an issue is demonstrated in the diagram above.

To establish numbers of young people with unmet need SEEMiS data could be used. Where young people tagged with a level of need/eligibility criteria who receive funding in children’s services and education at substantial and critical levels is compared to adult services (in the example below its level three and four respectively). We “should” be able to track across which pupils then receive a funded service from adult health and social care.

- **How can the shift of spending from reactive/acute services to primary/preventative services be speeded up and/or incentivised?**

Planning and decision-making should for services be done in partnership with young people and their carers. Section 4 of the Community Empowerment (Scotland) Act 2015 requires the community planning partnership to enable community bodies to participate in community planning. The partnership should identify ‘bodies [which] represent the interests of persons who experience inequalities of outcome that result from socio-

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31 Stalker, K (2013) It all comes down to money. Report for the Children’s Commissioner. HMSO
economic disadvantage.’ According to research carried out by Contact a Family this would include disability groups. Other areas would be youth forums, carers, single-parent families, and any groups that represent people with any additional need where they are economically disadvantaged.

**Best practice**

Young people and their carers often feel disconnected from the planning and commissioning processes that affect them. It is good practice that they are encouraged and given the opportunity to influence and inform the commissioning processes of local authorities (UNCRC article 12 and the Public Sector Equality Duties). Many young people and their carers will require support to develop the skills, confidence and knowledge to participate meaningfully in what are sometimes complex decision-making processes. Where these opportunities do not exist, efforts should be made to develop them. The co-production of services has a positive impact on commissioning the most needed and appropriate services.

’Age-banded’ or ‘age-dedicated’ adolescent clinics can provide a platform to reach young people to involve them in the exploration of opportunities needed in the community and in the development of existing services to enable a real difference to be made. Initiatives such as the National Standards for Community Engagement, Community Empowerment (Scotland) Act 2015 and Charter for Involvement provide useful frameworks to help structure and support involvement of this nature.

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33 Contact a family (2012) Counting the costs: The financial Reality for Families with disabled children across the U.K.
34 Combe (2002) Involving young people in local authority decision-making: An exploration of how local authorities can get young people involved in decision making. JRF.
35 http://www.coproductionscotland.org.uk
36 evidence of this can be found in the teenage cancer clinics
38 Scottish Executive (2015) Community Empowerment (Scotland) Act