The Highland Council

Education, Children and Adult Services Committee
27 August 2015

Agenda Item	29.
Report No	ECAS 75/15

Outcome of the consultation on Self-Directed Support

Report by Director of Care and Learning

Summary

This report outlines the process and the outcomes of the consultation with families regarding options under consideration in relation to Self-Directed Support (SDS), and some provisional views on future direction.

The Highland-wide consultation with parent/carers, children and young people, was commissioned from Highland Children's Forum, regarding the options to free up resource for implementation of Self Directed Support by re-shaping services. Further time is required to work through proposals, which will be reported at a future date.

1. Background

1.1 As previously reported, implementation of Self-Directed Support requires that social care resource is freed up by re-shaping services at the same time as reducing the overall spend.

1.2 This has not been achieved to date, except on a marginal basis, mainly because the bulk of resource is tied up in residential respite where staff posts are the main cost.

1.3 There are no easy solutions for moving resource, and the main purpose of the previous report was to outline potential options in moving forward with the redesign of services.

1.4 There is no established pattern in Highland on which to base the re-design. There are arrangements in place for families to choose a Direct Payment, but many continue to use a mixture of Direct Payment and traditional council services. Indeed many others, whilst wishing to have more control over service provision, also don't want to manage the budget for this, and so work in partnership with the council service.

1.5 The legislation allows for the possibility of a wider group of children and their parents/carers seeking to use Direct Payments to access services, including for those are not currently using council services, thus increasing the call on budgets which will need to be managed by shifting resources from council services.

1.6 The previous report to Committee outlined some of the options available to the Council for freeing up budget and their likely impact on service provision.

1.7 Given the significance of the decisions to be made and the ramifications for many families, the Committee felt that it would be beneficial to consult with children and young people and their families before making any final decisions. Members agreed to a proposal to consult with current and potential users of SDS on the options for change. Highland Children's Forum was subsequently commissioned to undertake the consultation.

2. The options developed for the consultation

2.1 The original objective was to consult current and potential recipients of SDS on the options for releasing budget from Council direct services, in order to maximise the use of the available resource for the uptake of SDS.

The five possible alternative approaches for the re-allocation of finance to allow self-directed support budget take up, are outlined in 2.3 below. While the financial decisions, which need to be made are complex, the principles behind them could be explained to allow people to prioritise between them, and perhaps to make suggestions of their own.

2.2 There is a set social care budget, out of which all 4 SDS options have to be funded. The purpose of re-allocating resources is to ensure equity across the wide variety of individual support requirements. Currently. that budget is committed to certain council services, such as residential respite provision at The Orchard, Staffin and Thor House.

2.3 At the moment, when a worker is Support Planning with a family choosing residential provision as part of their SDS package, the individual nights are costed at a subsidised rate. If the full rate were to be costed, families choosing residential respite might find that their budget did not buy them as many nights.

2.4 The same applies to some specialised holiday and after school play provision, which is subsidised in other ways.

2.5 The principles behind the financial alternatives for the Council are:

1. Should money be taken out of in-house services - thereby reducing their availability, to enable more money to be released for more people to use their budget in a different way to meet the outcomes in their plan (e.g. on ensuring involvement in community or local activities)?

2. Should residential respite care be reserved for those with the highest levels of need who would not easily be able to find other provision (due to physical or mental health or behavioural issues)? This would mean those places stopping other kinds of activities e.g. day care, after school support, group work etc.

3. Should residential respite be available to anyone choosing it at full cost (between £350 and £700 per night) meaning people would have fewer nights available to them? Or if the cost continues to be subsidised, everyone’s budget would have to be reduced.

4. Should money be re-allocated from support worker posts in Health and Social Care as people will be able to employ their own support workers or take up other opportunities?

5. Should the current Resource Allocation System (RAS) ‘pounds per points’ ratio be reduced to allow in-house provision to continue? Should the upper and lower limits of the budgets be restricted? This would mean the current funding would be spread more evenly between people, but almost all would receive a bit less money.

6. A few exceptional SDS packages are beyond the current top level of the RAS (£20,000) because of the level of need of the child or young person who might otherwise require provision out of Highland. Should there be an upper limit?

3 The consultation process

3.1 It was apparent that it would be difficult to go straight in to a consultation on this complex matter, without first ensuring that SDS was known about and understood by those participating. Accordingly, a two stage process was designed in order to get views and options from parents on how The Highland Council could best manage the necessary change and enable further up take of SDS.

3.2 The first stage of the consultation with families and young people, including those who have and those who have not been through the SDS resource allocation process, was to understand where families were at in their understanding of the options of SDS.

3.3 Time was taken in this stage to ensure that the values and opportunities of self-direction, regardless of the option chosen, were well understood - so that children and young people and their parent carers could make informed responses to the principles of the different alternatives for change.

3.4 In the second stage, the financial challenge faced by the council was explained in terms of seeking equity and managing the change period. The principles behind the alternative financial approaches were discussed, and people given the opportunity to prioritise and come up with other ideas.

3.5 Participants were also asked, as appropriate, if they would like to contribute further by becoming part of a critical reference group, which will consider the results of the consultation and the development of these principles with regard to the social care budget management through the change process**.**

3.6 Case studies were used to illustrate the impact of the different alternatives on the choices of children, young people and their families

3.7 With children and young people, self-directed support was explained and they were asked about outcomes - what constitutes a good life in their local area, who helps them have a good life and what they might like to do differently to meet personal outcomes?

3.8 The initial plan had been to present the consultees with visual case studies, to indicate the different principles behind the alternatives being considered by the Council and ask them to prioritise and comment on these and make suggestions.

3.9 Following discussion with the Children’s Disability staff it was decided and this was too complex, and so the second activity was scaled back. Instead, children and young people were asked to prioritise the activities and people they had talked about, that helped them to have a good life.

4. Outcome of the consultation by Highland Children’s Forum – Key Findings

4.1 The full report of the consultation is attached as **Appendix 1**.

4.2 It was recognised that the timescale for this consultation was very short to fit with the timeframe of ECAS meetings and to be able to present a report to this August Committee

4.3 17 children and young people were recruited to take part in the consultation.

4.4 Whilst these numbers are low, the information gathered gives an indication of preferences for certain alternatives. The key findings outlined on page 5 are:

- Most of the things that children and young people identified as helping them to have a good life were low cost and local.
- The one young person who had a support worker stated they had no choice in who that person was but would like to have a say.
- As only 5 participants accessed specialist services, we cannot draw any specific conclusions. However, all 5 were clear they benefitted from the services.

4.5 Specialist services did not appear to exist in the rural area. This may expose an inequity if specialist services continue to be subsidized.

4.6 10 parents were recruited to take part in the consultation. The key messages from them are:

- There is a lack of consistency across Highland in terms of knowledge and understanding of SDS
- There is a need to protect residential respite for those with the highest level of need for whom there is no alternative, appropriate provision
- While low level need can be met in low cost, local solutions, without that small budget families can tip towards crisis
- Parent carers feel they cannot make informed choices until they have an understanding of the real cost of subsidised or in-house services.

4.7 A key finding is that if there were support for planning and managing Personal Budgets, more people would choose Option 2 of SDS.

5. Immediate and longer term actions

5.1 Clearly, action can be taken immediately to address the lack of consistency of knowledge and understanding across Highland, and that is in hand.

5.2 It now appears crucial to make available the true cost of direct services, and analyse the impact of using the full cost of residential respite. Some of this work has been done and some is outstanding.

5.3 Work has also begun with the Residential Respite Managers to analyse any perceived changes in the pattern of usage which might help to forecast the need coming through, especially over the next 10 years or so, and consider what steps might be taken towards protecting those with greatest need.

5.4 More effort needs to be put in to building up alternatives to direct services, and thinking creatively about other ways to enhance a young person's life and improve inclusion in their community. The message is clear, that young people want small scale local activities.

5.5 The NHS Highland SDS Team are keen to encourage micro-enterprise and are currently engaged with 'Community Catalysts', who may assist to take forward such initiatives in Highland.

5.6 If there were support services developed for families to manage personal budgets and the responsibilities of being an employer, it might lead to more families choosing different options with their SDS budget, enabling creative routes to CYP children and young people achieving their outcomes, and ultimately reducing the need for and cost of in-house service.

5.7 'In Control Scotland' (the leading national consultancy on SDS) have been asked to prioritise Highland for their work with providers, and a number of events are organised over the remainder of this year.

6. Implications

6.1 **Resources:** The resource issues are included in this report. The operation of SDS is currently being audited by Highland Council Financial Services in line with the recommendations of Audit Scotland and a Report expected later this year. Any changes to provision will have to be achieved within existing resources.

6.2 **Legal:** Highland Council has committed to implementation of Self-Directed Support and managing the transformational implications of this change.

6.3 **Equalities:** It is acknowledged that those groups of children and young people with greatest need and their families who may experience less choice as traditional services are downsized need to be protected.

6.4. **Climate Change/Carbon Clever:** There are no climate change/carbon clever implications arising from this report

6.5 **Risk: T**here is a risk in pre-empting any established changed pattern of need and demand, by unnecessarily reducing some council services. There is also however a financial riskin continuing to provide the same level of services, whilst offering greater opportunities for families to access Direct Payments.

6.6 **Gaelic**: There are no Gaelic implications arising from this report.

6.7 **Rural:** The absence of specialist services in some rural locations may be further explored through a small scale pilot in a specific location. There are challenges in providing choice for families in rural areas.

7. Recommendation

7.1 It is recommended that the Committee notes the outcome of the consultation, and that a more substantive report on proposals is brought to the November meeting. These are likely to centre on:

- Down-sizing our residential respite provision and ring-fencing it for those with highest needs.
- Working on encouraging alternatives to residential respite for those who could make use of activity-based breaks.
- Allocating the full cost of residential respite through the Resource Allocation System.
- Introduce different criteria for accessing the centres.

7.2 It is also recommended that a workshop is held with members in advance of the November Committee to enable members to have more detailed discussion about proposals with relevant officers.

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Date: 17 August 2015

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Self-Directed Support: Getting the Best Value for Highland

Report to ECAS Committee

on Consultation with Children, Young People and Parent Carers

Highland Children's Forum

Anne Ross 2015

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Millburn Academy

Plockton High School

St Clement's Special School

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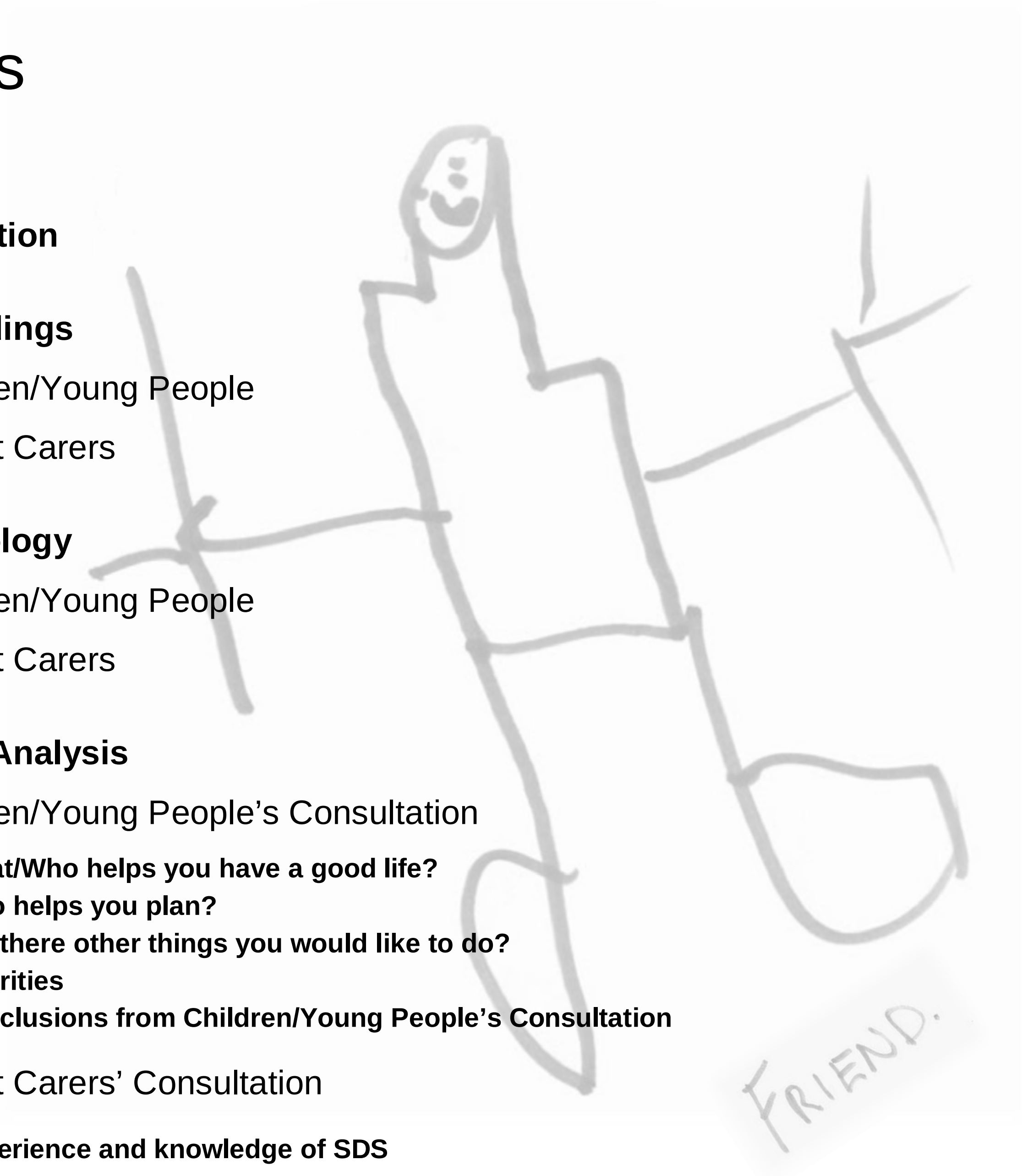


Introduction

In 2013 The Scottish Parliament passed a new law on social care support, the Social Care (Self-directed Support) (Scotland) Act 2013). Self-directed support (SDS) allows people to choose how their support is provided to them by giving them as much ongoing control as they want over the individual budget spent on their support. The Act places a duty on council's to offer people four choices as to how they receive their social care support:

1. Direct payment

2. The person directs the available support and the money is handled by the council or another organisation of their choice

3. The council chooses and arranges the support

4. Mix of options

By the end of 2014, The Highland Council Highland, were well into the implementation phase of actions to embed SDS in service delivery. However, this is a very complex change to the way services are delivered plus there is no new money for implementing SDS. The Highland Council was, therefore, presented with a real challenge: continuing to directly provide some services e.g. residential respite, whilst also supporting the move to SDS packages.

The Education, Children and Adult Services (ECAS) Committee of The Highland Council acknowledged that it was not sustainable for the Council to continue to 'double fund' ie directly fund services and fund SDS packages through Personal Budgets (PB) as people moved on to these. The committee had been considering the need for budget reconfiguration to allow money to be released for the implementation of SDS as families assessed as having eligibility began to opt for PBs. In February 2015, a report was presented to the ECAS committee outlining potential options to managing the social care budget. **(Annex 1)**

As this was a major decision to be made with ramifications for many families, the committee felt that it would be beneficial to consult with children/young people and their families before making a final decision; Highland Children's Forum (HCF) was asked to undertake a Highland-wide consultation on behalf of The Highland Council.

It was recognised that the timescale for this consultation was very short to fit with the timeframe of ECAS meetings and to be able to present a report to the August meeting. In spite of this, 17 children/young people and 10 parents were recruited to take part in the consultation. .

Key Findings

Children/Young People

- **Most of the things that children/young people identified as helping them have a good life were low cost and local**
- **The one child/young person who had a support worker stated they had no choice in who that person was but would like to have a say**
- **As only 5 participants accessed specialist services, we cannot draw any specific conclusions. However, all 5 were clear they benefitted from the services.**

  "[It's] for people who've had a tough life and stuff, changes…..You get to run around …and be yourself'

- **Specialist groups/activities* did not appear to exist in the remote rural area (see definition under 'Methodology') – does this expose an inequity if specialist groups/activities continue to be subsidised?**

Parent Carers

- **There is a lack of consistency across Highland in terms of knowledge and understanding of SDS**
- **There is a need to protect residential respite for those with the highest level of need for whom there is no alternative, appropriate provision**
- **While low level need can be met in low cost, local solutions, without that small budget families can tip towards crisis**
- **Parent carers feel they cannot make informed choices until they have an understanding of the real cost of subsidised or in-house services.**

  "Until I know what we would be charged and awarded, I don't feel I can really comment."

- **If there were support for planning and managing Personal Budgets, more people would choose Option 2 of SDS**

*'Specialist groups/activities' refers to groups/activities specifically set up to support children/young people with Additional Support Needs e.g. SNAP (Special Needs Action Project), Riding for the Disabled, Young Carers.

Methodology

The brief for the consultation was to consult with children and young people with Additional Support Needs (ASN) and parent carers across Highland on the principles behind the options presented to the ECAS committee. (**Annex 2)**

To ensure a demographic balance, the following types of area and schools were identified: **other urban area, remote small town and remote rural area** (as defined by the Scottish Government's Urban/ Rural Classification 2013-2014, 6-fold); two primary schools, two secondary schools and one special school. Parent focus groups and one to ones were offered in these areas as well as to parents using two residential respite centres. Parent carers involved in the SDS parent facebook group were also invited to participate. There were no respondents from the facebook group; this may have been due to the complex subject matter and nature of the consultation as several parents who participated commented that it helped to have face to face explanations and discussions.

Information and the invitation to take part went out to children/young people through the schools with consent being sought from both the children/young people and parent carers since access to SDS is dependent on parental choice. Parent carers were contacted through the Children's Disability Service, local parent support groups and the two residential respite centres. **(Annex 3)** The aim was to include a mix of parent carers who already used an SDS budget and those who did not but met the eligibility criteria.

Children and Young People's Consultation

17 children/young people were met with either individually or in groups of two. Where appropriate, children/young people were asked **what would make a good life for an imaginary person** coming to live **in their area.** Where advised by school staff that the children/young people would not identify with an imaginary person (the majority of cases), the interview went straight to **what and who helps you have a good life** (question 2) followed by **who helps you plan** (question 3) and **are there other things you would like to do** (question 4).

The original proposal was to return a second day with activities to explain the dilemma for the council to share the money fairly, look at the alternative approaches and prioritise them and ask if they had other ideas about what the council might do. However, in discussion with the Children's Disability Team, it was agreed this was too complex and so the second activity was scaled right back. Instead, children/young people were asked to **prioritise the activities and people** (question 5) they had talked about that helped them have a good life or that they would like to do. Signs representing 'Thumbs up/ thumbs in the middle/ thumbs down' were used to indicate top priority, slightly less important and not as important to them within their answers.

It had been acknowledged in discussions with the Children's Disability Team and Head of Children's Services that it would be impossible to consult with children/young people directly on the alternative approaches to managing the social care budget as these were complex concepts (not least for Councillors and officials!). It was felt more appropriate to concentrate on the above topics and find out what types of activity and people children/young people saw as important to their having a good life. For example, were activities local? At a distance? Specialist? Free? Costly? Who were the people important to them or who helped them plan - relatives? Friends? Paid workers? These results could then be used to inform the ECAS committee about children and young people's priorities for their lives and outcomes and help the committee as it considered where the social care budget was best directed.

Parent Carers' Consultation

10 parent carers were consulted through 4 focus groups, 1 one to one and 1 on their own after a phone conversation and being sent the information.

To set the consultation in context for parent carers, the first part looked solely at **SDS.** It was felt this was necessary to ascertain what participants knew and understood about SDS before asking them to consider and prioritise alternatives for managing the social care budget. Parent carers were asked **who was or was not on an SDS budget** and what **information** they had had **regarding SDS**. If people were not clear about SDS, the consultant explained more about it. Participants then discussed **examples of outcomes being achieved**, **perceived and actual challenges to having a PB**.

The second part dealt with **the principles behind the ECAS SDS Report options** and were presented in **4 alternative approaches**. It also looked at an **alternative 5**, which discussed the development of potential organisations to support SDS option 2, currently not available in Children's Services, and which could happen alongside any of the other 4 alternative approaches. **Case studies and graphics** were used to explain these alternatives, which participants took away with them to consider. **(Annex 4)** They were emailed a form with follow-up questions and contacted by phone or email (their choice) a few days later when they were asked to **prioritise the alternative approaches, comment on the development of an organisation for SDS Option 2** and if they had **any other suggestions. (Annex 5)**

Parent carers were also given the option of being part of a Critical Reference Group to discuss the analysis of the consultation responses.

Further Analysis

Children/Young People

The children/young people who participated in this consultation were a random sample from across Highland not a representative one as the range did not include, for example, severe physical disability nor sight impairment. This was not a deliberate exclusion; it was merely down to who volunteered to participate. This is what they had to say.

What/Who helps you have a good life?

Most answers fell into five broad categories - Outdoor, Indoor and Organised Activities, People, Pets. Within those, the top responses were: friends (10/11 groups), parents and computers (8/11). These were closely followed by TV (varied use of) and leisure centre/swimming (7/11). Just over half the groups (6/11) cited cycling, rollerbowl, social media, football (playing and watching) and pets.

What helped the majority of children/young people in the groups have a good life was a blend from all five categories.

"Swimming… it's healthy and good fun"

"Family that stands by you"

"Friends…to hang out with and play X-box"

"[Drama club] so much fun and my mum's really proud of me for doing some of the stuff"

"Getting him made me feel glad and happy" [pet rabbit]

Who helps you plan?

Parents headed up the responses (8/11) with 4 groups stating they also did a lot of their own planning. Only 1 child/young person mentioned having any formal support in terms of a Social Worker and Support worker but was clear they were important in helping them plan.

Are there other things you would like to do?

Although the interviewer was fully prepared to manage expectations when asking this question, in actual fact, there were no 'big asks' in the responses. 23 suggestions were made; the range was, unsurprisingly, very individualised i.e. each identified by only one or two groups, and included having a trampoline, attending the odd, professional football match, accessing particular subjects at school and being able to choose their support worker. (This latter is particularly important in terms of meeting the principles of SDS).

Priorities

Children/young people put the majority of activities and people they had identified in questions 2 and 4 beside the 'Thumbs up' sign. The main, top priorities for children/young people were: their parents; friends; the leisure centre/swimming; computer.

In the middle category of being slightly less important to the children/young people, (although still within the context of what they saw as helping them or what would help them have a good life) responses, on the whole, were again very individualised e.g. social media (2/11), cycling (1/11), football (1/11). The exception was friends with 4/11 groups placing them here.

Overall, only 7 activities were highlighted as being not as important to them within their priorities. These fell under Outdoor and Indoor Activities categories.

Conclusions from Children/Young People's Consultation

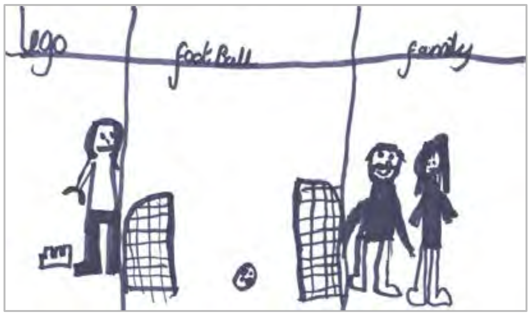
- the vast majority of responses were what we would expect children and young people to like doing or want to do regardless of whether they have any additional support needs i.e. some outdoor activities, some indoor, some organised or specialist, some not, spending time with friends

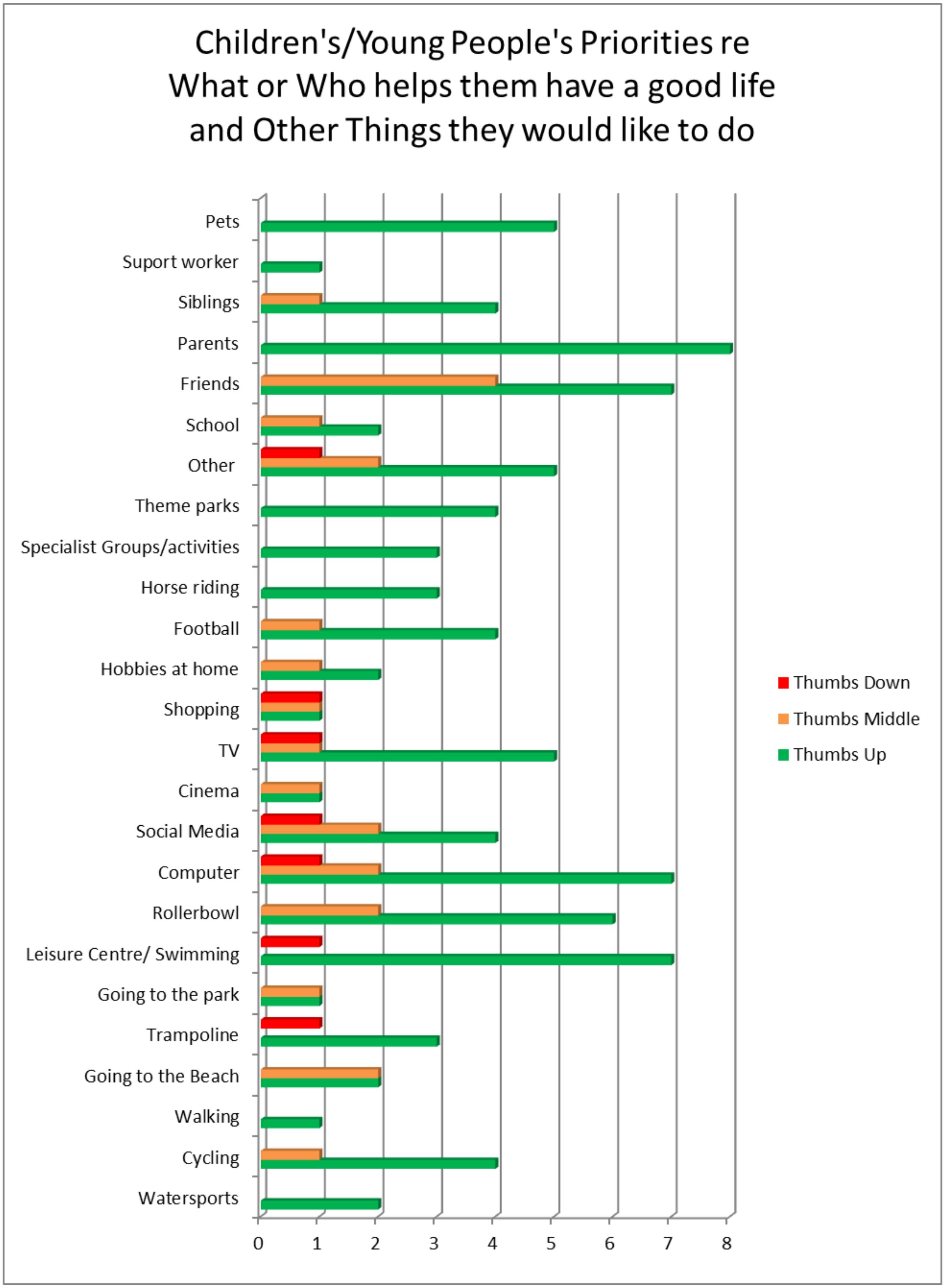
- the main people who helped the children/young people plan and who they saw as important to them were parents and friends. However, it must be remembered that, in this consultation, only 1 child/young person mentioned having a social worker and a support worker, identifying that they were important to them and helped them plan. 2 of 5 who attended specialist groups/ activities also did so regarding their group leaders
  "… if you didn't have any [friends], you would be alone and you need friends to do sports with"

- what and whom the children/young people identified as helping them have a good life or things they would like to do were, on the whole, accessible within or close to their own communities. Although one or two groups in the remote rural area did mention having to go elsewhere for certain activities, only one group talked more negatively about having to have their parents take them outwith their immediate community to access these e.g rollerbowling and summed it up by saying "it's easier if you can do things where you live"

- activities identified and classed as a 'thumbs up' tended to be low or no cost

- of the 17 children/young people spoken with, 5 mentioned accessing specialist services. These services were either in an other urban (Inverness) or remote small town area. The children/young people in the remote rural area who mentioned accessing a specialist group/activity had to travel outwith their area to do so





Children's/Young People's Priorities re What or Who helps them have a good life and Other Things they would like to do

‘Other’ grouped together activities mentioned by only one group and which did not easily fit under the main headings e.g. ghost-hunting.

Parent Carers

Experience and knowledge of SDS

Of the 10 parent carers who took part, 4 were already on an SDS budget and 6 were not although 2 (from the same family) were in the midst of transferring to one.

Regarding the level and quality of information the 4 parents received before they chose the SDS route, 1 did not comment, 1 felt their prior information had been little or poor, 2 felt they had been well-briefed by their social worker.

Of the 6 who were not yet on an SDS budget, 1 did not comment, 4 felt they had had little or poor information, 1 felt they had had good information from relevant professionals and could make an informed choice if the time came.

Perceived and actual challenges to having a Personal Budget largely concurred: being an employer; finding appropriate workers; breakdown of resource (e.g. worker off sick or leaves); lack of suitable, local resources. A couple of parent carers who had a PB highlighted the challenge of not being clear on what the PB could be used for. There were other anecdotal references to parent carers known to participants who were also struggling with this issue.

A clear message from this part of the consultation was that there is inconsistency across Highland over the information on SDS being given to parents. It appears to be very dependent on which professionals support parent carers and their (the professionals') understanding of SDS.

Responses to the 4 alternative resource management approaches and the development of potential organisations for SDS Option 2

The 4 resource management alternative approaches parent carers were asked to consider were:

1. **Maintain a subsidy for in-house residential respite.**
2. **Charge the full cost for in-house residential respite.**
3. **Keep residential respite for highest needs only and stop subsidy for specialist activities, in-house support workers**
4. **Limit the highest and lowest budgets**

Parent carers commented on how difficult they had found this part of the consultation. This was not just in terms of grasping complex concepts; it was also because they had struggled to balance what they felt was the priority for their child or young person and family with the approach they thought might better suit the majority of children/young people and families across Highland. One also pointed out that the alternative, which was best for them now might not remain so in the future should their child/young person's needs change. For one parent carer, it proved too difficult an exercise as they already felt overwhelmed by the complexities of SDS and the lack of comprehensive information on it to guide them in their situation. As a result, they did not feel able to comment on or prioritise the 4 alternatives. Another indicated they did not like Alternatives 2 and 4 but could not prioritise between Alternatives 1 and 3.

The alternative approach favoured by the largest number was **Alternative 3 Keep residential respite for highest needs only. Stop subsidy for specialist activities and Local Authority support workers - 5/10**

The following are the pros and cons of each alternative as perceived by the parent carers**.**

Pros: it protects those with highest needs but ‘highest needs’ should not have a cut-off; it gives parent carers more responsibility when looking for specialist activities and means they would have to think carefully about how they spend the PB; stopping the subsidy would encourage families to look at what their children/young people really needs and benefits from and might lead to cheaper, locally-based support; this could mean some people having more money than before but they would need to be wary of how they spend it as the specialist activities would cost more.

Cons: it would deny those with high, though not the highest, needs diversity in their life and social interaction opportunities; stopping the subsidy would reduce choice, one of fundamental justifications of SDS; it would mean the loss of a highly-valued resource in local authority support workers.

A few parents commented that it would be helpful to have a clear definition of what constituted both ‘highest’ and ‘lowest’ needs.

Responses to the other alternatives were:

Alternative 1 Maintain a subsidy for in-house residential respite – 3 /10

Pros: many people look to respite for a chance to either recharge their batteries or spend time with other children “safe in the knowledge” their child/young person is happy and well-cared for; would sustain an excellent and reliable resource; better to give everyone who needs it, some kind of [respite] support.

Cons: lacks flexibility if it is not working well for child/young person but there are no alternatives; if money went into PB instead, it would give more choice and might encourage local solutions and facilities (which would take costs down); everyone [else] loses out as with the bulk of budget maintaining respite, there would be little for children/young people and families who still need some, though less intense, support.

Alternative 2 Charge the full cost for in-house residential respite – 1 /10

Pros: suits respondent’s circumstances best and also possibly others if their PB was amended; would encourage using and developing more local support workers/ facilities, which would be better for both children/young people and families rather than having to travel often a long distance to the in-house respite.

Cons: concern families would be put off due to cost and so might risk service disappearing; the high charge for respite would mean that people have less money to spend on respite, which some rely on; the number of nights' respite families had were what they felt they needed and so were very anxious if these were to be reduced.

Alternative 4 Limit the highest and lowest budgets - 1/10

Pros: if hard choices need to be made, children/young people on the lower limit may have more choices of things they can do and other options that do not cost money (e.g. Duke of Edinburgh pupils' supporting them).

Cons: it penalises both ends of the need spectrum; upper limit is taking money from those already in a hard situation; people on the lowest budgets may be relying on that small amount to prevent things escalating; could force a lot of people into more stressful lives, which in turn could lead to more unnecessary medical conditions on all members of the household.

Other **general comments and suggestions** on the 4 alternatives included: the approach to resource management needs a blend of all 4 alternatives as none would work on their own; concern that if it proves not possible to maintain the level of subsidy for residential respite, it might either go altogether or go into the private sector, where it could still be cut as it would not have the financial safety net local authority provision has; if alternatives to specialist activities exist then there should not be a subsidy as that penalises those who could not get a place in the subsidised one. However there should still be a subsidy where there are no alternative resources e.g. families use residential units as no alternatives - costs may need to increase but should still remain affordable to families; where a family has an allocated pattern of residential respite and, well in advance, cancels a session as something else has cropped up (e.g. family event), assuming that session is re-allocated to another child/young person, what happens to the original child/young person's funding? There needs to be a means of costing out all council provision, so that if child/young person doesn't use it, the funding goes back into their pot to be used in alternative ways.

Alternative 5 SDS Option 2 – Encourage the development of local Co-operative/ Community Interest Company/ Voluntary organisations for Option 2 (when someone else manages the budget).

In response to the question **'If such an organisation existed, how would this affect your choice of Self-Directed Support option?**', **5 out of the 9** parent carers who answered stated they would choose that option; **3/9** were interested in Option 2 but with reservations; **1/9** said they would probably not use as they were confident of managing the PB and all that entailed themselves.

Pros: having the full PB and control of it but with someone else having the responsibility of the day to day management of the budget and doing the payroll; allows for wider and more creative options for child/young person;

would provide support and guidance for families, especially regarding activities and opportunities for child/young person; would help with finding and employing support workers; support workers would be suitably trained or skilled; a mediator if conflict or different opinions between budget holder and Social Work; an official body responsible for employer's liability, health and safety, etc.

Cons: depends on what services it offered; how much the fee for any services would be; the fact any fee takes away budget from the child/young person.

Conclusions of Parent Carers' Consultation

- a general acknowledgement, regardless of personal circumstances, that children/ young people with high needs required some protection of resources as their options might already be very limited
- equally, 6 participants commented that those at the lowest end also needed safeguarding as that small budget might be preventing the child/young person and family from "tipping over the edge"
- a very real concern from those whose child/young person used or had used residential respite about what would happen if this resource were reduced or disappeared altogether. They commented on how it provided their child/young person with reliable, quality care, peer and other social interaction while allowing the family to have a much-needed break or parents to spend time with their other children and do other things with peace of mind
- if the kind of organisations proposed in Alternative 5 existed, 8/9 participants who commented would then opt for Personal Budgets. This suggests there would be real value in further exploration of the development of such organisations

Annexes

Annex 1. Extract from Self-Directed Support Report to ECAS Committee 11:02:2015

3.6 Officers are therefore seeking to initiate a consultation process in order to establish views on the future pattern of delivery. Options have been developed as a basis for consultation, but it may be that other options emerge from the consultation process. The options developed to date are outlined in the following sections of this report. Through consultation it is hoped that new types of services may be identified which could better meet the needs of families.

4. Gate-keep residential provision and reduce as funds are moved to SDS

4.1 Highland Council has very well established residential respite provision, at The Orchard, Thor House and Staffin Respite Centre. To date, few families have opted to reduce the use of these resources. The options for freeing up resource, which require a reduction in the level of staffing include:

4.2 **Option 1:**

- Contract provision to the 'core' group of children with complex heath needs and significant disability.
- Restrict provision to residential respite and cease all other activities such as day care, after school support, group work, and outreach.

4.3 **Option 2:**
Amend the Resource Allocation System (RAS) to reflect the true cost of residential respite provision, instead of the subsidised amount utilised to date in order to cushion the implications on residential provision. (This would require review of all SDS Support Packages approved using the subsidised rate.)

5. Reshape support work services using all available budgets to obtain better value for money.

5.1 **Option 3:**
The Support Work Review, reported separately to this Committee, will result in additional funding for Self-Directed Support. At the same time, the pre-existing staffed support work requires to be re-shaped to avoid the risk of double spend. Essentially, this means continuing the move away from support worker posts into more flexible budgets.

6. Review the maximum level of the Resource Allocation System (RAS)

6.1 The work undertaken to date to develop an equitable Resource Allocation System was based on an exercise costing 60 current packages and, utilising a financial formula, allocating points along a sliding scale. This resulted in five levels for the RAS, ranging from under £2,000 to a top level of £20,000. This work was based on current spend not on current budget.

6.2 **Option 4:**
Reducing the value of the whole RAS by an agreed amount, for example £5,000 with a top level of £15,000 and change the allocation of pounds to points. This would bring it more in line with budget.

7. Limit the total package available for SDS and prioritise children with highest needs

7.1 Currently there are a number of SDS packages which are well over the £20,000 limit. These are exceptional cases of high need and the packages are thought to reduce the risk of the greater expenditure of accommodating a child or funding an out of authority placement.

7.2 **Option 5:**
The maximum level for the additional resource could be set at a reduced level.

Annex 2. SDS Consultation Proposal 2015

Why

Self-Directed Support in respect of children's services in Highland has one further year of additional funds to allow for some new families to take up Direct Payments without impacting on the level of current in-house service provision for those who wish to continue with it. It is not clear what the long-term demand for self-directed budgets will be. Currently, Highland is still trying to find children's service providers for option 2 from the legislation, offering brokerage or managing Individual Service Funds.

A proposal was presented to the Education, Children and Adult Services Committee in February 2015 containing five possible alternative approaches for the re-allocation of finance to allow self-directed support budget take up. While the financial decisions, which need to be made, are complex, the principles behind them can be explained to allow people to prioritise between them and perhaps to make suggestions of their own.

For children and young people and their parent carers to make informed responses to the principles, time will be taken to ensure the values and opportunities of self-direction, regardless of the option chosen, are well understood.

There is a set social care budget out of which all 4 SDS options have to be funded. The purpose of re-allocating resources is to ensure equity across the wide variety of individual support requirements. Currently that budget is committed to certain council services, such as residential respite provision at The Orchard, Staffin and Thor House. At the moment, when a worker is Support Planning with a family choosing residential provision as part of their SDS package the individual nights are costed at a subsidised rate. If the full rate were to be costed, families choosing residential respite might find that their budget did not buy as many nights.

The principles behind the financial options for the council are:

1. Should money be taken out of in-house services, thereby reducing their availability, to enable more money to be released for more people to use their budget in a different way to meet the outcomes in their plan e.g. on ensuring involvement in community or local activities?
2. Should residential respite care be reserved for those with the highest levels of need who would not easily be able to find other provision (due to physical or mental health or behavioural issues)? This would mean those places stopping other kinds of activities e.g. day care, after school support, group work etc.
3. Should residential respite be available to anyone choosing it at full cost (between £350 and £700 per night) meaning people would have fewer nights available to them? Or if the cost continues to be subsidised, everyone's budget would have to be reduced.
4. Should money be re-allocated from support worker posts in Health and Social Care as people will be able to employ their own support workers or take up other opportunities?
5. Should the current RAS pounds per point's ratio be reduced to allow in-house provision to continue? Should the upper and lower limits of the budgets be restricted? This would mean the current funding would be spread more evenly

between people, but almost all would receive a bit less money.

6. A few exceptional SDS packages are beyond the current top level of the RAS (£20,000) because of the level of need of the child or young person who might otherwise require provision out of Highland. Should there be an upper limit?
7. Should there be support services developed for families to manage personal budgets and employer's liability? This might lead to more families accessing an SDS budget, enabling creative routes to CYP achieving their outcomes, and ultimately reducing the need for and cost of in-house services.

What

Objective – to get views and options from CYP and parents on how THC could best spend the SDS budget.

This will be a two stage project. In the first stage, there will be a consultation with families and young people including those who have and those who have not been through the SDS resource allocation process, to understand where families are at in their understanding of the options of SDS available and of the benefits of self-direction, whatever the option chosen is. The financial dilemma faced by the council will be explained in terms of seeking equity and managing the change period. The principles behind the alternative finance approaches will be discussed and people will have the opportunity to prioritise and come up with other ideas.

Children and young people will have self-directed support explained and be asked about outcomes- what constitutes a good life in their local area, who helps them have a good life and what they might like to do differently to meet personal outcomes?

CYP who are able and willing, will be presented with visual case studies to indicate the different principles behind the options being offered to the council, and asked to prioritise and comment on these and make suggestions.

In the second stage, participants will be asked, as appropriate, if they would like to contribute further by becoming part of a critical reference group (CRG), which will consider the results of the consultation and the development of these principles re the social care budget management through the change process**.**

When

April – July 2015

Timetable – info out to services before Easter hols (2nd - 17th April)

Mid-May into early June consultation

Rest of June – involvement of CRG in discussions of analysis leading to final conclusions and recommendations

July – Final report

Who

CYP with ASN in two secondary schools, two primary schools and one special school

Parent carers identified by CDS who already use SDS budget – including some from 1st Steps

Parent carers identified by CDS who do not have an SDS budget but who meet the eligibility criteria

Parent carers through parent support groups in specific localities

Parent carers whose CYP access particular services such as residential respite or specialist out of school

SDS Parent Carer Facebook group

Where

Covering the urban, rural and super sparse areas of Highland:

Millburn Academy, Inverness

Plockton Secondary

St Clement's School, Dingwall

Inshes Primary, Inverness

Mount Pleasant Primary, Thurso

Parent carers in Caithness and Alness/Tain areas

Skye & Lochalsh area through families who use Staffin

Through families who use the Orchard

[**Terminology** later changed to **other urban area, remote small town and remote rural area** using Scottish Government's Urban Rural Classification, 20013-20014, 6-fold, to better reflect Highland areas]**.**

How

Parent carers

Caithness and Easter Ross: 1 focus groups in each area; 1:1 interviews (by face or phone)

Orchard and Staffin parents: a focus group if possible, if not some 1:1 interviews (face to face or by phone)

Use Facebook to consult with the Facebook parent group. If this does not appear to work, do some 1:1 interviews (face to face or by phone)

Consultation plan:

- Address to those without SDS: what do you know about SDS
- For those with SDS: what information did you have before choosing SDS route and what can you share now
- Explain move from old deficit model to new outcome-focussed model for child and also for family
- Ask for examples of activities, which have led to progressing outcomes

- Share good examples
- Those without SDS: what do perceive as the challenges in having a personal budget
- Those with SDS: what have the challenges actually been
- What could be done to overcome these barriers

Introduce case studies to demonstrate the principles behind the ECAS paper options as presented to the council. Parent carers will be given these to take away and think about. They will be contacted within the next few days by phone or email and asked to prioritise between these principles and make suggestions. (See Appendix 1)

CYP

Information will be provided for both CYP and their parents in advance of the consultation. CYP with capacity over the age 12 will be deemed able to give their own consent. However in this instance, as access to SDS is dependent on parental choice, we would also seek parental consent for all CYP.

Focus group, 1:1 and other participation opportunities with CYP as advised by support staff.

Using imaginary person if appropriate, if not relate to their lives:

- What would make a good life for X in your area?
- What helps you have a good life?
- Who helps you plan or do things?
- Are there other things you would like to do? (managing expectations)

For those who are able to contribute further the next day:

- Explain the dilemma for the council to share the money fairly
- CYP to look at the principles and be asked to prioritise between them
- CYP to be asked if they have other ideas about what the council might do

Stage 2

Development of Critical Reference Group from participants.

Analysis of consultation responses will be carried out and the results shared with CRG for discussion over a fixed period of time

The final report will incorporate these discussions.

Annex 3. Participant Information and Invitation

Children/young people's letter:

Highland Children's Forum

Representing Children and Young People with Additional Support Needs in Highland
Listening to children and young people: speaking with Policy Makers

Hello,

Your views matter to the Highland Council - Would you like to help them?

Highland Children's Forum (HCF) is a voluntary sector organisation, which listens to children and young people who have Additional Support Needs. What children and young people say is then used to help services get better at what they do.

The two staff members are Anne Ross, Consultation Lead and Gillian Newman, Policy Lead.

We are coming to your school on **………………………** and invite you to take part in an activity with us. You can take part in a small group, one to one or in another way that suits you. Taking part is voluntary and you can stop at any time.

The first day we will ask about:

- What would make a good life for someone moving into your area?
- What helps you have a good life?
- Who helps you plan or do things?

If you enjoy this activity, you are invited to another meeting the next day when we will:

- Talk about some important decisions The Highland Council need to make
- Give you some stories to help you think about those decisions
- Ask you what you think is important and if you have other ideas

The activities should be fun and no more than 45 minutes long.

If you want to take part we need you to speak to your parents. Then you and your parents need to fill out the forms we have sent. Remember, this is voluntary and you can stop at any point. What you say to us is private, unless you say something that makes us think someone is at risk of harm.

We hope you will take part.

Yours,

Parent Carer letter:

Highland Children's Forum

Representing Children and Young People in Need in Highland

Listening to children and young people: Speaking with Policy Makers

Dear Parent,
This letter is to invite you to be involved in an important consultation at **………………** on……….
Mileage will be reimbursed.
Self-Directed Support (SDS) legislation became law a year ago. It means that families are provided with a personal budget when assessed as eligible for social care support due to the disability or additional support needs of their child.
The budget is intended to add value to what is already working well for families and ensure that they have more choice and control over how to improve the outcomes for their child and family.
Please see the leaflet enclosed/attached regarding the options available to families to make best use of their budget.
To date, some families are choosing to use their budget in new and creative ways. Others are taking a more measured approach and continue to make use of existing services. Others might have a mixture of the two.

Due to this change in the law, The Highland Council may need to change how it spends its social care budget now and for the future to make sure that it is spread fairly to those who need it and that all of the SDS options are made available.
There are various alternatives as to how this might happen. **The Council are keen to take account of the views of both parent carers and children/young people to help them make those changes**. They have asked the Highland Children's Forum (HCF) to carry out this exercise.
HCF is an independent voluntary organisation with a long history of consulting with children and young people with additional support needs and their families.
We are offering an up to 2- hour parent carer focus groups with a follow up task requested by email/letter/phonecall.
If you would like to take part, please contact us using the details below. If you can't come to a focus group, there **may be the opportunity to take part through one to one interviews** (face-to-face or by phone). Please ask using the details below.
Once the results of the focus are analysed there will be an opportunity for those who are interested to be further involved.

Yours, Anne Ross, Consultation Lead

Highland Children's Forum
New Start Highland Offices 9 Carsegate Road North Inverness IV3 8DU
www.highlandchildrensforum.org info@highlandchildrensforum.org
07789680811

Annex 4.

(i) Case Studies

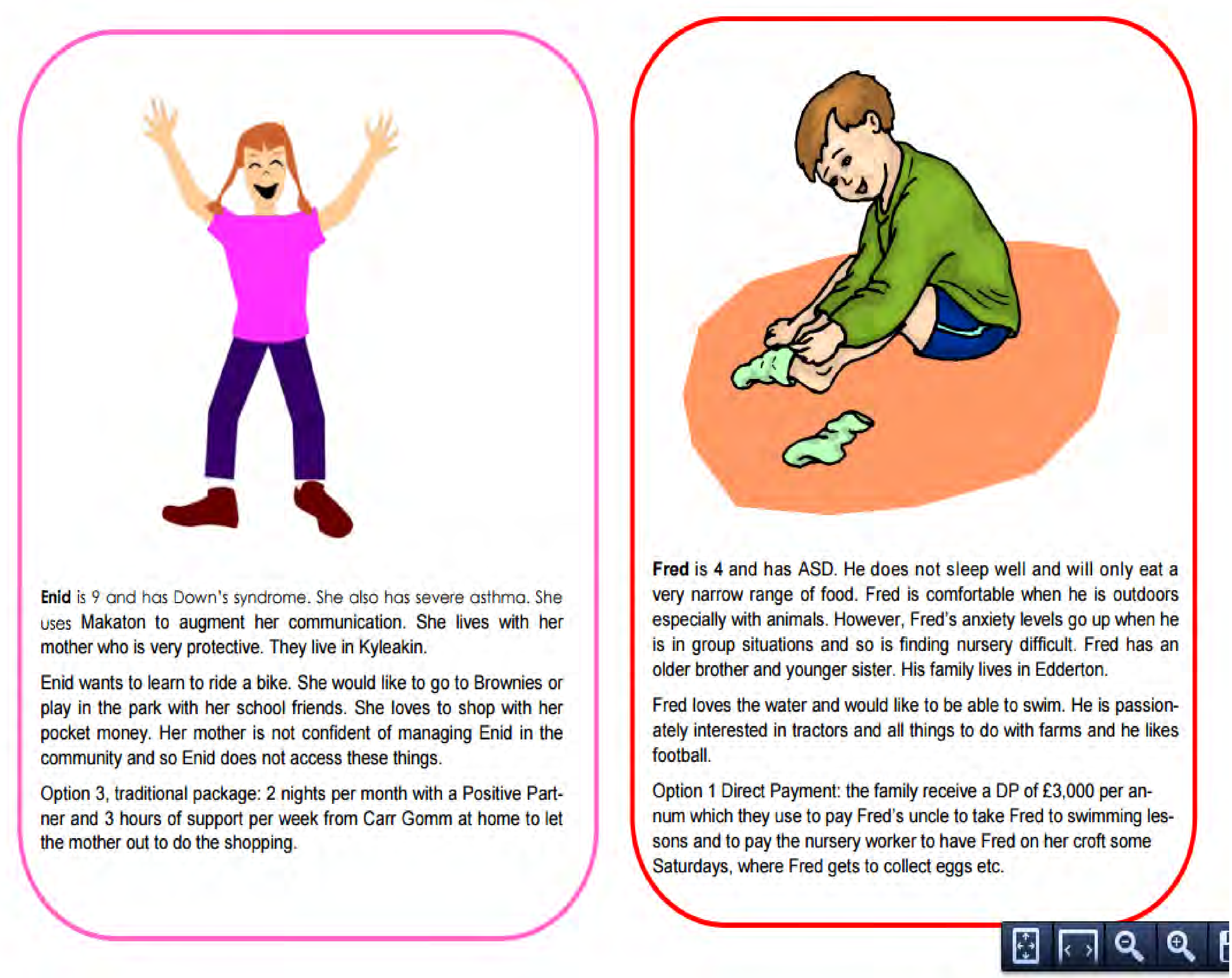
Sylvia is 16 and is a wheelchair user. As Sylvia is moving towards transition, she is being supported to increase her confidence and move towards greater independence from her parents. The family lives in rural Caithness, a few miles from Lybster. Sylvia has an older sister who now lives in Dundee. Sylvia loves music and singing but is very shy.

Option 3, traditional service: Sylvia has accessed social care services since early childhood. She currently gets 2 nights per month at Thor and 4 hours per week direct service from support workers. Due to the fact that the family have a Disability Mobility Allowance, the parents now take Sylvia to and from Thor. The support worker is trying to encourage travel independent of her parents by using the accessible bus from Lybster to Wick.

Simon is 14 with profound ASD, epilepsy, behavioural difficulties, needs two people for his safety (strong and can bolt). He has three siblings, one of whom is possibly on the spectrum but does not have a diagnosis. Simon can be violent to his siblings at times. The family are currently just coping. They live in Nairn.

Simon loves running and tends to bolt in any direction. He loves playing with War Hammer miniatures and playing computer games.

Option 4, mixed package: 1 night per week at The Orchard, attends SNAP and has a DP £7,000 per annum, which is spent on support from Direct Childcare to have help at home so his siblings can go out with the parents or sometimes Simon is taken out to the War Hammer games shop.



Enid is 9 and has Down's syndrome. She also has severe asthma. She uses Makaton to augment her communication. She lives with her mother who is very protective. They live in Kyleakin.

Enid wants to learn to ride a bike. She would like to go to Brownies or play in the park with her school friends. She loves to shop with her pocket money. Her mother is not confident of managing Enid in the community and so Enid does not access these things.

Option 3, traditional package: 2 nights per month with a Positive Partner and 3 hours of support per week from Carr Gomm at home to let the mother out to do the shopping.

Fred is 4 and has ASD. He does not sleep well and will only eat a very narrow range of food. Fred is comfortable when he is outdoors especially with animals. However, Fred's anxiety levels go up when he is in group situations and so is finding nursery difficult. Fred has an older brother and younger sister. His family lives in Edderton.

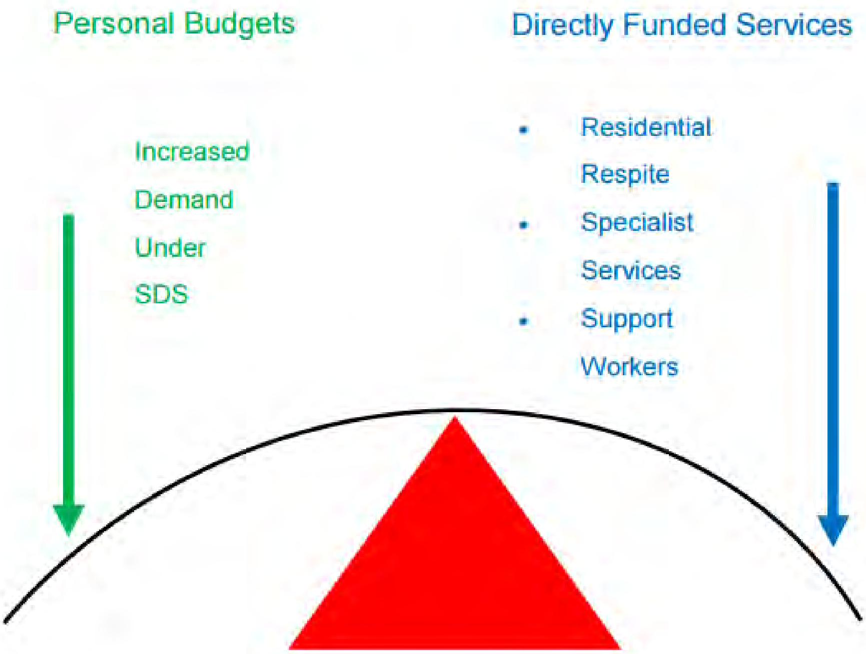
Fred loves the water and would like to be able to swim. He is passionately interested in tractors and all things to do with farms and he likes football.

Option 1 Direct Payment: the family receive a DP of £3,000 per annum which they use to pay Fred's uncle to take Fred to swimming lessons and to pay the nursery worker to have Fred on her croft some Saturdays, where Fred gets to collect eggs etc.

Annex 4

(ii). Social Care Budget Alternatives Leaflet

Highland Children's Forum
Consultation on Self-Directed Support
Social Care Budget Alternatives



Personal Budgets

Increased
Demand
Under
SDS

Directly Funded Services

- Residential
  Respite
- Specialist
  Services
- Support
  Workers

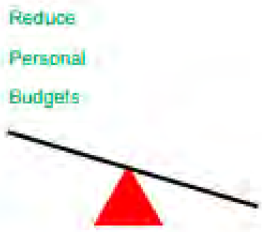
Balancing the Social Care Budget
Currently Over-stretched

Resource Management Alternative Approaches:

1. **Maintain subsidy for residential respite.**

Reduces the current pounds per point calculation but people can purchase respite or specialist activities at a reduced cost.

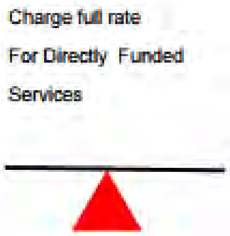
Assumption: **more desire for in-house respite than using personal budgets**



2. **Charge full cost for in-house residential respite.**

Pounds per point calculation would remain about the same but the cost of respite would increase or even double.

Assumption: **option of in-house respite as well as increased access to community-based opportunities.**



3. **Keep residential respite for highest needs only Stop subsidy for specialist activities & LA support workers.**

Increased pounds per point calculation with reduced access to and increased cost of Directly Funded services .

Assumption: **most people want to access personal budgets and community-based activities**.

4. **Limit the highest and lowest budgets.**

Maintain the current pounds per point calculation and some subsidy of in-house services. People with small budgets would lose them. The small number of people on the highest budgets would have reductions.

Assumption: **it is better to give most people a little more even if it means that a few people with the highest needs get less or lowest needs get none.**

Alternative Approaches for the Case Studies:

1. Maintain a subsidy for in-house residential respite.

Sylvia's package would be unchanged.

Simon would maintain his one night of residential respite but would have a smaller personal budget for community-based activities.

Enid's package would be unchanged.

Fred would receive a lower personal budget.

2. Charge the full cost for in-house residential respite.

Sylvia's respite would be reduced to one night per month.

Simon's respite reduced to one night per fortnight but no change in his personal budget. Sessions at SNAP would be charged at full cost .

Enid would pay full cost of Positive Partnership respite.

Fred would continue to receive the same personal budget.

3. Keep residential respite for highest needs only and stop subsidy for specialist activities and in-house support workers

Sylvia may keep respite depending on cut off for "highest need" . Sylvia would need to employ support worker through personal budget.

Simon would keep his respite and may have an increase in his personal budget but the cost of any specialist services/support workers would go up.

Enid would lose her respite but might have the opportunity to have other respite through her personal budget and possibly be able to try new things.

Fred might have an increase in his personal budget.

4. Limit the highest and lowest budgets.

Sylvia's package would remain the same or improve slightly.

Simon would be on the edge of the cut-off for highest budgets. It is likely that his package would be reduced. The family may be able to choose between reduction of personal budget or of respite.

Enid's package would remain the same or improve slightly.

Fred would be on the cut-off point for losing his package altogether.

5. Encourage the development of local Co-operative/Community Interest Company/Voluntary organisation for Option 2 (when someone else manage's the budget.

This could happen alongside any of the alternatives. It would be a new service whereby, for a small percentage of the budget, the personal budget would be managed and creative support plans enabled. This would give people the freedom of choice to access community activities without the hassle of managing a budget and employer's liability.

Assumption: **it is in the interests of all to build up community capacity and inclusion so that most people can access these activities and opportunities without the work of managing a personal budget**.

Sylvia could move on to a personal budget in preparation for transition. The organisation could help Sylvia and her parents think of creative ways of meeting outcomes e.g. access a voice coach to increase her confidence, fund singing lessons, try an arts and craft course in Lybster to meet other people.

Simon would be able to access this service for his personal budget. The organisation might be able to match Simon with a support worker who runs him/herself and therefore who can offer a regular run for Simon, or help him join the local Harrier group, which may help him sleep better and improve other aspects of his wellbeing.

Enid's mum might be willing to access support planning from the organisation for a personal budget so that Enid could try to do some other things e.g. buy a bicycle and use some support hours to learn to ride, pro-social peers could learn Makaton and buddy Enid to the park and other places, support worker hours could be used to help Enid settle into the Brownies. Support could be withdrawn when Enid was happy and included.

Fred could continue his swimming lessons and perhaps other support workers could be found from the organisation for him to try other activities e.g. a young person doing their Duke of Edinburgh award might take Fred to the park for a kick about. The employer's liability for the nursery worker or Fred's uncle could be processed through the agency.

This alternative would enable more families to take up personal budgets and benefit from the flexibility and creativity that this offers, without the additional work and worry of the paperwork. It might encourage the growth of alternatives for short-break options. It might offer support into mainstream activities with a planned withdrawal as inclusion improves. The organisation could lobby and support communities and community services to become more inclusive.

Annex 5. HCF Consultation Response Pro Forma

Highland Children's Forum Consultation Response re:
Self-Directed Support Social Care Budget
Alternatives before The Highland Council

Alternatives set before The Highland Council:	Please provide your views about and priorities for these alternatives bearing in mind the case studies presented in the leaflet.
1. **Maintain subsidy for residential respite.**	
2. Charge full cost for in-house residential respite.	
3. Keep residential respite for highest needs only Stop subsidy for specialist activities & LA support workers.	
4. Limit the highest and lowest budgets.	
Outside of THC, another organisation might offer SDS Option 2, see below:	If such an organisation existed, how would this affect your choice of Self-Directed Support option:
5. Encourage the development of local Co-operative/Community Interest Company/Voluntary organisations for Option 2 (when someone else manages the budget).	

The Highland Council are also interested in any suggestions families might have about how to manage the social care resources for children and families:

If an organisation were to offer support for Option 2 of SDS, what do you think you would need or want that service to provide?

Do you have any other comments that you would like to make about this consultation?

Thank you for your time and contribution.

Please return form to: anne@highlandchildrensforum.org or HCF, New Start Highland Offices, 9 Carsegate Road North, Inverness, IV3 8DU

Annex 6. Participants

Children/ Young People

The breakdown of the 17 children/young people who took part in the consultation is as follows:

Area	
Other Urban	4
Remote Small town	7
Remote Rural	6

Age range

Ages ranged from 6 – 17 years old: 7 from primary school; 8 from secondary; 2 from a special school.

Parent Carers

The breakdown of the 10 parent carer participants is as follows**:**

Area	
Urban	5
Remote Small town	2
Remote Rural	3

Number using or who had used a residential respite centre – 6

Areas as defined by [the Scottish Government's Urban Rural Classification 2013-2014, 6-fold]