Agenda Item	11.
Report No	ACS/25/14

The Highland Council

ADULT AND CHILDREN'S SERVICES COMMITTEE

19 February 2014

Self Directed Support

Report by Director of Health and Social Care

Summary

This report sets out the critical issues that need to be considered by the Council as part of the implementation of Self Directed Support.

1. Background

1.1 Delivering Self-Directed Support (SDS) in Children's Services in Highland

The Social Care (Self-directed Support) (Scotland) Act 2012 is to be fully implemented from April 2014. This new legislation has raised the profile of Self Directed Support (SDS), and requires NHS Highland and The Highland Council to actively promote the take-up. Indeed, Highland Council has committed to do this within its Programme.

1.2 Direct payments have been available for support to children with disabilities since the introduction of the Direct Payment legislation in 1996. The implementation of SDS from April will continue to focus on this group of children, including those in transition to adulthood.

1.3 SDS provides eligible families with 4 options namely:

1. Direct Payment (cash payment)
2. Individual Budget held by a provider of the family's choice, known as an Individual Service Fund
3. Council arranged service
4. A combination of these

1.4 There has been a 5-6% increase from 2012 to 2014, in numbers of families accessing a Direct Payment for their child/ren, with an effective 11% increase in the value of weekly packages.

1.5 Many of the Direct Payments (82 at present) are part of a package of support which also contains some in-house provision and purchased care or support.

2 Resource Allocation System

2.1 Until this year, Direct Payments were based on providing funds to the equivalent costs of the direct service for which the family were considered eligible. During 2013-14, the Highland Council in partnership with NHS Highland and in line with national policy and the principles of the legislation, has been developing a Resource Allocation System (RAS) for Children's Services.

2.2 The aim of the RAS is to provide a score, which is then converted into an Indicative Budget. The RAS is considered a less subjective and fairer way of sharing resources, and much more empowering for families.

2.3 The SDS Team employed an independent consultant to support the development and testing of the RAS and the associated Guidance. As the Highland RAS is based on the SHANARI Wellbeing Indicators, it reflects a holistic view of the needs of a child and the family.

2.4 The Children's Disability Service has worked in partnership with the consultant and the Finance Section to develop the RAS. This involved a range of tasks, including the costing of in-house services. The process and methodology, including the development of guidance, is outlined in the Evaluation Report, attached as Appendix 1.

2.5 A 'Test' RAS was developed and trialled with the families who signed up for the First and Second First Steps Pilots.

2.6 The newsletter, Stepping Out (Appendix 2), was compiled to celebrate the success of the second Pilot with a group of families who were given a relatively small amount of money to use creatively over the school holiday period to improve management of what is typically a stressful time for them.

2.7 The Cameron family describe how their lives have been transformed by being able to make their own choices about how to meet their needs. The cost of their package of support has subsequently been reduced. In other cases, the Indicative Budget for supporting families is considerably in excess of the provision currently made for them.

2.8 The RAS remains a work in progress. Learning from this process has involved setting the RAS weighting at an amount which will allow adjustment, as increasing use is made of it, and the impact continues to be evaluated in partnership with families. This has to reflect the real cost of providing support to families, while also being affordable.

2.9 However, it is worth taking full account of the final quote in the Evaluation Report:
'Children are making progress towards outcomes in ways the family had not dreamed would be possible, and parents and siblings have also benefitted from the changes. Choice and control have empowered these families to build on their real wealth and deliver better outcomes for the whole family.'

3 Implementation

3.1 There are a number of challenges for the Local Authority as we move forward (which are being experienced across the country) and these are summarised in the following quotes from a Scottish Government Social Research paper:

> *'The expansion of SDS in Scotland is not uncontentious. The aspirations for improved empowerment, choice and control which drive the policy are broadly supported by all the stakeholders involved in this project. However, it is not yet clear that SDS can deliver all it promises, particularly in the era of resource constraints and significant pressures on social care budgets'.*
>
> *'There are concerns about where costs will fall, and what the impact of SDS will be on different sectors. Implementing SDS policy will require, to a certain extent, a 'leap of faith' for Local Authorities'*.
>
> COUNTING THE COST OF CHOICE AND CONTROL: EVIDENCE FOR THE COSTS OF SELF-DIRECTED SUPPORT IN SCOTLAND 2012

3.2 The specific challenge now is how to upscale from the relatively small scale year long trial, to a full scale implementation, at the same time as building in a potential saving as we review the existing packages and begin new SDS packages.

3.3 Support for staff will also be required, to implement an initiative that could potentially involve them no longer being required in current roles, as SDS reduces the need for Council staff and services.

3.4 Most importantly, it will be necessary to look at restructuring the Council budget as we move forward and release cash for direct payments from some or all of the following traditional services:

- Childcare
- Support Work
- Residential Respite
- Home Based Respite
- Fieldwork
- Care at Home

3.5 The management of these new requirements and a possible increase in demand for services within an already stretched budget, must involve planning for the release of resources currently tied up in traditional services. This complete systems change will require continued financial management support.

3.6 The context of this exercise is the continuing pressure on all of the service budgets for children with disabilities, evidenced in the review of Additional Support Needs, involving:

- Increasing levels of complexity of need as result of the success of medical intervention
- Increasing numbers of children affected by Autism Spectrum

Disorder and by Foetal Alcohol Syndrome

- The number of children and young people on part time timetables or not in school.
- A significant proportion of children with disabilities grow up in single parent families, affected by lower income as well as disability.

3.7 It is also the case however, that:

- There is a strong case that the choice and empowerment intrinsic to services provided through self-directed support, can be more effective services that lead to better and earlier outcomes for children and families.
- Services funded via self-directed support can often be more cost effective than traditional services.
- Direct payments are a more flexible model of support, and can be increased and reduced as need changes.
- Many direct payments are preventing more expensive, long term traditional services from becoming necessary. Indeed, some may be preventing children from requiring to become looked after.

4 Release of resources

4.1 Child Care

As child care is largely spot purchased, the aim is to release specified amounts over the next 3 years to increase the budget for direct payments. This process will be subject to review if the situation changes more rapidly.

More work is required on this as not all of the Teams have such a budget.

4.2 Support Work

As members are aware, there has been an on-going review of Support Work; the final outcomes of which have still to be reported.

However, it is clear that many SDS requests will be in lieu of Support Work, and accordingly that some in-house staffing costs will require to be converted into funding of direct payments.

4.3 Residential and Family Based Respite

It is not clear whether families may wish to use direct payments as an alternative to residential respite. However, if they do, this will have significant implications for existing services – either through downsizing or closures.

Each provision is examining if there are ways to reduce provision, as families chose Direct Payment instead of residential respite and ways to generate income from those already in receipt of a Direct Payment e.g. by the provision of day care or outreach.

The same applies to Family Based respite as experience has shown that this is an option which more families would wish to access than we are able to provide.

More work is required with Area Managers, Managers and workers to clarify the way ahead in these areas, as any patterns of changing demand may indicate the need for a much more radical strategy.

4.4 Home Based Respite

Currently, there are pressures on the budget for spot purchase of home based respite. This is being actively reviewed with a view to also releasing funds for direct payment.

We are also assessing the level of home based respite provided which compensates for the difficulty in accessing care at home/personal care (see below).

4.5 Fieldwork

We need to consider and identify whether fieldwork costs may be reduced by SDS. The philosophy is that giving more control to families to direct and manage their support gives them more choice and better outcomes, and will in time lead to a reduction in need for fieldwork staff to manage their case.

There is some evidence from Highland Council's Children's Services history with Direct Payment that small Direct Payments have succeeded in maintaining some children and young people at a relatively low level of support with minimal input from a Lead Professional. The opposite is the case with more complex packages of support, where regular review by the Lead Professional has been required in partnership with the family

4.6 Care at Home

It is likely that a significant number of families will wish to use self-directed support for personal care, as an alternative to care at home provision.

NHS Highland is the main provider of Care at Home for children, and it is likely that this service will require to be decommissioned.

There is however a mismatch between the level of demand for Care at Home for children, and the current level of provision. For some time now, it has proved difficult to access Care at Home, because of the pressures on the service from meeting the needs of older people – and the consequence is that it has been referred to far less frequently by Children's' Services staff.

The Children's Disability Teams estimate that a significant level of purchased support and home based respite is in lieu of care at home, and thereby contributing to the current over spends in these budgets.

Work is on-going to better understand the actual need for Care at Home services. If this was comparable to the share of the total budget that is accorded to children's home based respite, which is 17%, it would represent just under £3m of the overall Care at Home budget.

5. Implications

5.1 Legal Implications

Highland Council will require to be able to implement the new legislation from April 2014.

5.2 Financial Implications

The implementation of Self-Directed Support is intended to be transformational in its impact The expectation is that families will be better able to meet their needs with the resource that is available, because they are in control and making the choices themselves about how to meet their needs.

There is still work to be done to keep the SDS budget within the resource available. It will be necessary to agree a limit at which to set Indicative Budgets to reflect the Health and Social Care element of the RAS. An emerging budget strategy will be required to manage this process, taking account of the issues set out in this paper.

All of the above requires infrastructure both to support on-going review of the RAS weighting system and continued the costing of existing packages.

The Pilot has also shown that much more work is required with staff to achieve a fuller understanding and impact on their practice.

Families already in receipt of a Direct Payment and direct services will need encouragement to move to more creative use of their budget. This will require further training with families for implementation to be effective and to develop ways with them to measure outcomes.

It is intended that the SDS Implementation monies are used to fund additional specialist financial advice and guidance to support the next phase of implementation.

The Implementation Group will continue to give a focus and provide an overall steer and ensure equity across Highland. It will be necessary to develop new processes to agree Indicative Budgets, including for high level cases.

5.3 Risk Implications

This is a significant development. Highland Council is well placed to take it forward, having been one of the national pathfinder sites. However, it will continue to require close and measured implementation, and incremental planning.

5.4 Equalities

There is a risk that SDS may be a favoured option for those groups of children and families who are able to use it, but that there will as a consequence be less choice and poorer access to services for other groups, as traditional services are downsized.

Recommendation

Members are asked to consider and comment on the issues raised in this report, to agree to progress the release of resources, and to seek further reports as these various activities are taken forward.

Bill Alexander
Designation: Director of Health and Social Care

Date: 9 February 2014

Author: Marlyn Campbell, Development Manager (Disability)

Report on the Development of the Resource Allocation System for Self-Directed Support in Children's Disability Service Highland

By Gillian Newman 2013

Contents:

Introduction

The initial project was to develop the documentation for Self-Directed Support (SDS), including the Resource Allocation System (RAS), in children's services in the Highland area. The draft documentation was to be trialled with families, evaluated and then a second trial carried out. This project was put to tender which was won by an Independent Participation Professional (IPP), ensuring that consultation and involvement of families and professionals was built in to every stage of the documentation development. The Authority's Representatives (AR) group were set up to oversee the project; it included the SDS team manager and senior managers in children's services from health, education, social care and finance. Nic Crosby from In Control was in attendance to advise and bring a national perspective.

Care First training was provided to the IPP to ensure understanding of the Care First system used by social care services. The IPP also attended a national SDS event in Edinburgh to begin to understand the national picture of RAS developments. As well as regular attendance at AR meetings, the IPP had monthly meetings with SDS team manager to ensure good communication during the project.

Early in the project, the AR took the decision for Highland Council to take part in the "Taking the First Steps" national trial for SDS in children's services. This meant the first and second family trials were held to coincide with the national timetable using the agreed methodology. The original timescale set did not recognise the complexity of RAS development so the AR and IPP agreed amended timescales between the first and second trials to allow the finance team to carry out back-office calculations.

The "Taking the First Steps" trial was so successful in bringing forward both family and professional understanding of SDS, that a second group of families were offered the same opportunity in October 2013.

Focus group of young people
"What makes a good day?"

This report describes the process of development of the RAS and associated documentation for children's services in Highland. It includes information about the consultation and involvement of families, professionals and service providers. The process of editing and redrafting the documentation, with involvement of families and professionals, is described. There is also an analysis of the case study exercise that was used in the development of the RAS involving both finance and children's disability teams. The Taking the First Steps trial and evaluation are discussed along with the participation of the subsequent families in the October 2013 trial. Family evaluation of using SDS is shared, including the opportunities and challenges experienced.

The report concludes on the effectiveness of the process of developing the RAS and also on the developments families perceive will be required for SDS to enable them to deliver improved outcomes for their children. Final drafts of the SDS documentation are included, along with newsletters, which share the family experiences from the each of the trials, in appendices.

Information Gathering and Consultation Phase

The IPP carried out desktop research in to the background of SDS and the development of RAS in England. Further research included looking at other countries and how different approaches to SDS were developed elsewhere. Beyond SDS, the research included documentation more generally on the personalisation agenda and the move from a deficit and need-based focus of social care services to an outcome based one.

Initially the IPP met with a range of people to ascertain their view about how SDS might work in children's services and what the key criteria would be for a good RAS. This consultation phase involved meeting people across the Children's Disability Service (CDS). Three focus groups were set for parent carers and a range of parent carers invited, although only 11 took part. Young people (in transition or recently through transition in to adult services) were also involved in three focus groups. The Highland Child's Plan was under review at that time, and different members of professionals tasked with the review were consulted. Service providers were also consulted, including in-house respite provision. Each person consulted was asked if they would be willing to be part of a Critical Reference Group (CRG) for the continued development of the documentation, receiving and reviewing each stage of the documentation.

The IT person tasked with creating the documentation for the Child's Plan and the IT person responsible for the development of Care First were also consulted.

Further consultation developed as the initial families from the Taking the First Step trial became part of the CRG. When the Social Care (Self-directed Support) (Scotland) Act 2013 was passed, an SDS implementation group in children's services was initiated with the IPP in attendance. This group expanded from the AR to include the wider CDS team and area managers and some service providers.

The IPP also attended some CDS team meetings to share different stages of the documentation development and involve the team in contributing to the case study exercise.

The council finance team for children's services came on board as the first versions of the documentation were developed and the IPP worked closely with finance and CDS with the case study exercise.

Focus group of young people
"What makes a bad day?"

All references and bibliography on page 15

Drafting Resource Allocation System

Many of those consulted expressed the hope that a RAS would be more equitable in terms of providing support to families. There was a perception that currently those who shouted loudest sometimes seemed to get the most; the current system was not transparent enough. A system that was visibly fairer would be welcome by all.

From the initial consultations, the desired criteria for the RAS was that it would be part of the Child's Plan (CP). The CP already had an assessment of strengths and pressures in the child's life and had identified desirable outcomes for the child. This approach is a good fit with SDS, which seeks to build on the "real wealth" of family and communities in terms of what they can contribute to progress outcomes for the child. Guidance from In Control was that the budget should be set before an action plan was developed. The RAS was, therefore, to become an optional section in the CP, relevant to those children who would be eligible for a social care budget, and would be completed with the child and or family by the social worker or key worker from social care after the assessment.

Most RAS systems studied had identified outcome domains against which a level of need could be measured. In the CP there are SHANARI outcomes (safe, healthy, achieving, nurtured, active, respected & responsible and included), which are nationally accepted. The CP My World triangle (MWT) assessment process recognises both the strengths and pressures in the child's health and development, the family situation and the community in which the family live. It was seen that either SHANARI or MWT could shape the domains of the RAS.

Through the sharing of early variations of a RAS, a version was agreed which chose the SHANARI headings as domains and identified 4 outcome statements under each, two for the child's own health and development, one for the family capacity and resilience and one for the child and family's engagement with the community (Appendix 1). The wording of this changed through review (10 versions) until the final version was agreed (Appendix 2). The initial version measured the variation in levels in terms of frequency of support. This was the current measure of service allocation: hours of respite. So the language for the levels was "support needed occasionally, sometimes, often or always". As the outcome focus developed with the trials it became clear that frequency is not the most useful measure. It was changed to "small, moderate, high or exceptional level of support required".

In recognition that some outcomes are either not an issue for that child or are currently met by the family, there is an option for each of these, which indicates no budget is required at the current time to meet these outcomes.

At a national meeting, another local authority had added an outcome about the impact of past trauma on the present. The AR recognised that things such as post-traumatic stress, mental health issues, substance misuse issues or unresolved grief in the family could significantly impact on the wellbeing of the child. So for a while, this outcome was added to the RAS. Through review it was decided that this was not a separate outcome, but one that fitted in the nurture domain.

The RAS was added as Section 8 to the new Child's Plan at an early stage of the RAS development, so is no longer the most up-to-date version, as it still contains the frequency measure.

It was recognised that the budget for different outcomes would not be same; some outcomes would be a priority. If a child is not safe, for example, then they cannot be healthy, active, or anything else. Staff from the CDS were asked to suggest a priority for each outcome from a range of 1, not a high priority, to 6, highest level of priority. Some put most outcomes at level 6, which did not allow for much variation. Staff were then given a limited total score, which they had to divide up between the outcomes, which worked better. An average scoring was taken from these to develop a range of priority outcomes. During the case study exercise, a weighting scale for these priorities was developed and honed in time to provide an indicative score that made sense across the range of case studies. This weighting scale can be altered if the roll out of the RAS produces results suggesting a particular outcome score should be higher or lower. For example, it become clear that the indicative budget was low in a couple cases where personal care involved use of a hoist and required two adults. The score for "F" in the outcome "to be fit and healthy" was increased to reflect this.

Drafting the Guidance

Parent carers at the original focus groups requested that more information about Self-Directed Support be made available to them. The My World Triangle tool was used in the focus groups and parents suggested that more information about Getting it Right Processes and the Child's Plan would be helpful too. Parents wanted to find out and share information about different services which were inclusive, websites that were useful, advice about easy ways to manage a Direct Payment.

The CDS wanted guidance on using the RAS to try to ensure that all members of staff used it in a similar and equitable way.

The guidance notes were drafted, shared and redrafted again and again as understanding developed. Nic Crosby and Jennifer Campbell contributed a great deal to the development of the early drafts; parent carers and professionals from the CRG and IG were involved in each edit.

Hopefully the resultant guidance (version 21) is clear and able to help people reach a consistent and realistic score for families in the future.
The other information in the guidance re services and choices for using SDS is incomplete, but as complete as information provided to IPP would allow. The final version of the guidance can be seen in appendix 3.

Katie, Bec And Morna each enjoy a Grand Day Out

Stories in 1st and 2nd Newsletters Appendices 6 & 10

Training on the Guidance should enable staff to know:

1. The RAS score is to allocate a social care budget; it is not an assessment. The MWT is still the assessment of strengths and pressures. The RAS follows the assessment.
2. The process should be empowering and hopeful for the families. It should build on the "real wealth" or strengths of the child, family and community and look positively at how outcomes might be achieved. It is not deficit focussed.
3. The range of scores to which a budget is attached is 'C' the lowest level to 'F' the exceptional level. This represents the entire range of need in the CDS. For each outcome, the Key Worker should mentally consider the range of need across children for that outcome to help decide where this child falls.
4. The system is to enable equity; if there is inconsistency between workers and some tend to seek higher levels of budget than others, it will affect the total number of pounds per point available to all.
5. How to score family and community outcomes if the family has more than one child entitled to an SDS budget

Case Study Exercise Set up

In the initial consultation period, a number of case studies were presented to the IPP, which helped clarify questions about the RAS. Adult services had carried out a desktop case study exercise to test the RAS and the AR took the decision to seek 100 case studies from the CDS to try out the current RAS.

Four people from CDS came together to work through some case studies. The first one in each instance took a long time as people analysed and discussed what was meant by each outcome. However, once the first one was complete, subsequent case studies were completed more quickly. By the end of the day there were 20 complete case studies.

At a later date, at a whole team meeting CDS staff were asked to carry out a RAS on up to 3 cases each. This exercise was useful as people were able to discuss, ask questions and reach decisions about scores; both the guidance and RAS were further edited. With the addition of families from the trial, 100 case studies were completed.

Finance designed a spreadsheet that meant the scores of A-F across the domains could be put in for each case and the indicative budgets were automatically generated so they could be compared. The weighting of each outcome score could be adjusted and the effect on indicative budgets across the 100 case studies seen. This provided a range of scores from small to large packages; however, more detail about the individual cases was needed to decide if the scores were fair.

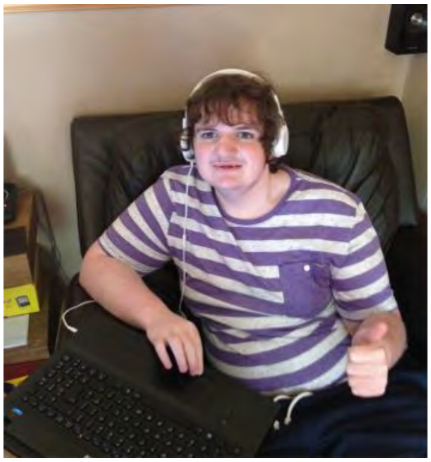
It was unfortunate that the Care First numbers had not been asked for in the case study exercise, as identification was difficult after the event.

Case holders were asked to provide details of the current packages of identified children. This was not a simple exercise as the respite hours people received varied over the year. A menu of options currently available to social care was developed and the input was the number of hours/sessions/nights used by the child weekly in term time, weekly in school holiday, weekly all year round, monthly or annual. Case holders found it difficult to complete the forms with current packages and this exercise took much longer than anticipated.

The finance team had been tasked with finding out the unit prices for each of the menu of options. This was not an easy calculation due to variations in service level agreements, use of council buildings, sessional fees. In-house services had not been calculated in unit costs, a complicated task as the requirements of children ranged from those who require complex nursing care to those who are more independent. These difficulties for the finance team led to delay in the timescale of the project.

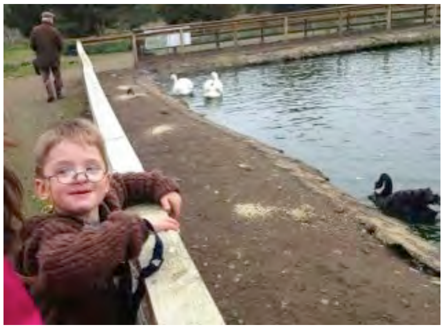
John Angus with a medal won for archery.
Story in 2nd newsletter
Appendix 10

Music opens up a new world for Douglas
Story in 1st newsletter
Appendix 6



Case Study Exercise

Developing the weighting scoring system



Joseph, trying new things Story in 2nd newsletter Appendix 10

Eventually, the spreadsheet was able to provide information on many of the cases so the current package could be compared to the RAS indicative budget.

Many of the scores in the middle range of cases produced an indicative budget close to the current package. However the indicative budget for cases which were on a high or low current budget were not a close match. Altering the outcome weightings automatically updated the indicative budgets. This allowed some different versions of weighting to be tried before a weighting was arrived at which made sense across a good number of cases. The cases where the discrepancies between current package and indicative budget were largest were considered one by one. It was realised that many of these had been completed early in the development of the RAS and that the score would be different if redone with the current understanding.

It was decided to begin a new case study spreadsheet with fresh cases, which were well known and understood. By this time the trial families were on to the second phase of piloting the RAS and so were included. The IPP visited area team meetings and each person present brought one case and did a RAS using the current guidance and completed a current package for the child. This provided a smaller number of cases, but which were better understood.

Generally, the indicative budgets made sense when the current package and family situation were considered. While there was not a close match in all cases, the discrepancies were better understood. The greatest variance still tended to be at the lower end or at the higher end of the scoring.

For those cases for whom the score is >400, these children or young people tend to be at the last stage of support before residential accommodation for the child would be considered. While the level of need was deemed to be reasonably reflected in the scores of >400, the bespoke nature of the potential solutions makes it difficult for the points=pounds calculation to hold true. It has been suggested by the IG that scores of this level might automatically be referred to a senior management board for agreement.

For those cases where the score is <80 the families are likely to be tipping into services and still at an early intervention stage. When the level of budget is small, even a small change is a significant percentage of the budget. In cases of early intervention, it may be that an initial lower level budget is tried with an early review to indicate if any change is needed.

Sometimes the indicative budget differs from the current package because the family have either been resistant to support or have made heavy demands on support, which may seem disproportionate to the need. This does not mean the score and indicative budget are incorrect, rather that the current package is not an equitable reflection of need.

Sometimes the budget differs in the same direction over a number of cases from the same key worker. This would suggest a training issue with the Key Worker. If the RAS is completed using the guidance consistently, then a family should receive more or less the same score regardless of which Key Worker completes the RAS with them.

Case Study Exercise

Reaching a conclusion

Another issue that arose was when a family have more than one child who is eligible to an SDS budget. For each child there would be a score for the family and community outcome in each domain. There was a query raised about whether there might be duplication in the score of support required which would mean the family received more budget than was equitable.

However, there might be some variance between the children for the family outcome. For example, under the outcome "for the family to have a healthy home life", one child may sleep all night and the other sleep only for 3 hours. For some outcomes, the need will be cumulative. For example if you live rurally and require access to specialised medical care, this challenge will be magnified if more than one child has such a need. The fact that the family has more than one child with additional support needs at home and in the community will of itself present challenges. Therefore, two complete scores are more likely to be equitable, with the pressures on the family considered in the knowledge of the score for the other child/children. In terms of training, it might be decided that the child with the most significant need has a RAS completed first so the family know the needs that are captured in that first score and can consider the additional support needed for the subsequent child or children.

Overall, the scores were deemed to be equitable or at least sense could be made of the score compared to others. The decision was reached that there was no advantage to playing further with the weighting system.

In cases where there is still a significant difference between indicative budget and current package, the decision may be taken to cap the change to a maximum percentage and review this to see if it meets the family need or if the next percentage change should be applied.

In total there were 32 versions of the case study RAS before the final weighting and scoring system was reached which was felt to be as good as it could be with current knowledge and experience. Appendix 4 provides the final spreadsheet with the smaller number of cases and includes the worksheets from which the calculations were made.

A spreadsheet for ongoing use by the CDS has been made ready, appendix 5. The RAS scores have been input for the pilot and trial families for whom this information is currently available.

The front worksheet provides instructions for Key Workers inputting information. It also provides suggestions about authorisation and access to the other worksheets for editing or other purposes, as any change will affect budgets across the caseload.

The total scores across the caseload and the total budget commitment can be seen in the scoring spreadsheet. Once more cases have been input, this should be a good indication to CDS managers about the overall spend and whether it is within an expected range. As this is reviewed it may be decided to alter either the weighting of particular outcomes or the pounds per point calculations.

Ideally, in the long term, Key Workers would be able to input the scores directly on to Care First to generate the indicative budget. This would require the scores to be transcribed from Care First into a hidden spreadsheet and then the indicative budget to appear back in Care First in the child's file. The hidden spreadsheet would be able to produce statistics across the caseload for managers of services. Authorised personnel, as mentioned above, would need to be able to alter the weighting or pounds per point calculations if review indicated the need for this.

Taking the First Steps Trial

Once the AR had taken the decision for Highland to be part of the Taking the First Steps trial, the IPP, In Control and the CDS worked closely together on the planning and delivery of the trial. The AR took the decision to include children or young people from the Children and Families Service (CFS). The trial involved giving families £200 to spend in the summer of 2012 to do something a bit different to help their child make progress toward an identified outcome.

The CDS identified 16 families for the trial and the CFS identified 4 families. Families came from across Highland; 2 from Lochaber, 6 from Caithness & Sutherland, 8 from Inverness, Nairn, Badenoch and Strathspey, 4 from Easter Ross. The families included children from infancy to aged 17. The range of disabilities included physical disability, learning disability, young people across the autism spectrum and a child with a rare genetic condition. Some families had more than one child with a disability. Families from the Children and Families Team included young parents, parents who had been in care themselves, children who had been in care, families affected by social, emotional and behavioural issues.

The IPP met with families in the first instance to explain the project and seek informed consent. Where families could be brought together, group meetings were arranged where Jaynie Mitchell of In Control came along to help in the support planning. Where families were not able to attend a group meeting, the IPP and Jaynie Mitchell visited them at home. From this families had a plan with one or more identified outcomes and some planned activities for spending the £200. In return for this, families were to collect the story of their summer and the difference the £200 had made. They were provided with a disposable camera and journal, but told that they could use other means of telling their story if they preferred.

As this was part of a national trial, other local authorities were following the same process elsewhere. The hope was that families and their Key Workers could develop creative ideas of how even a small amount of money could be used to make a real difference to outcomes.

The trial was successful in both opening family minds to the possibilities of SDS, but also in developing the understanding of Key Workers. Some families had had a remarkable success in terms of meeting outcomes, saying this had been the best summer ever for them, others had limited success and two families had been unable to spend the money in the summer period.

A family event was held in the autumn bringing together families, workers, managers, service providers and others to hear the family stories and to consider together the potential that choice and control over a budget, even a small budget, had in terms of delivering improved outcomes for children and families. An evaluation report of the Taking the First Steps trial including family information and the newsletter of family stories is in appendix 6.

We see amazing things on the swings,
We feel like we have wings on these swings,
Like a butter fly in the sky,
With joyful laughter and a tear in my eye,
By Sapphire sunshine Morrison
Age 10

Family story from 1st newsletter, appendix 6

Trial: Next Steps

The summer £200 trial was the first phase of the Taking the First Steps trial. A second phase was that these families would go on to pilot the new RAS (family information in appendix 7). A decision was taken at that point to focus on families from the CDS and families from the CFS were not involved further. The families were to complete the RAS with their Key Worker and the indicative budget compared to the current cost of the package of support they received, which across the families included the 4 budget options in the SDS Act (2013).

These families have proved incredibly helpful in shaping the wording of the guidance. They were provided with an evaluation form (appendix 8) about their experience of SDS and how effective it was in delivering better outcomes. This information contributed to the lessons learned and recommendations of this report.

As Taking the First Steps had been instrumental in moving forward the understanding of both families and workers, the implementation group took the decision to repeat the £200 trial over the October 2013 holidays. CDS workers who had not been involved in the first trial, were asked to identify a family for this second trial. 16 families were identified who were visited by the IPP to have participation explained and consent forms completed (appendix 9). The IPP also did the planning session with families.

As the October holidays are only two weeks long, some families spent the money over October and into early November. The stories from these families have been brought together in a second newsletter (appendix 10). A second family event was held in November 2013, to which both the second trial and the pilot families were invited along with professionals, service providers, managers and others. While the turnout at the event was disappointing, families and staff said in feedback that they had benefitted from hearing different family stories. The opportunity to network and meet others had also been really useful and there was a feeling expressed that such opportunity to network was a useful way of generating and sharing ideas.

Stories from 2nd newsletter, appendix 10

Timothy enjoyed the opportunity to spend time and do supervised activities with a friend from school. This enabled them to have fun together, communicate and make friends. The support meant that both Timothy and Alan had the time and freedom outside of the school environment to connect and do things they would not normally do.
"During the October holidays, I spent two really fun days doing various activities with my friend Alan. We both go the Charleston Academy and that is how we met." Timothy

Matthew (16) had been talking about his goal for some time. He wanted to become more independent by accessing the local bus service without a carer. Despite Matthew's intense phobia of crying babies he was determined to achieve his goal and with this extra support (and a set of noise cancelling headphones) he was able to succeed.

Information from Evaluations and Feedback Form

- Perceived benefits of SDS
    - Flexibility to use budget to deliver outcomes not just pay for support hours
    - Ability to purchase equipment
    - Use money to support children accessing mainstream activities
    - Allows child to choose and pursue own interests or hobbies
    - Promotes independence in children and young people
    - Enables choice of support worker
    - Can produce unexpected benefits to others or to child in other ways
    - Allows needs of whole family to be considered
- Challenges to SDS working
    - Can be very hard to find support workers who can do odd hours
    - Recruiting the right support and getting suitable training is difficult for individuals
    - Employers liability is a huge responsibility and challenge
    - Lack of local opportunities or suitable options available mean that money is unspent and outcomes are not met
    - While parent carers manage personal care on a 1:1 basis, health and safety rules can require 2:1 at school. There are safety issues in providing personal care 1:1 but it is difficult to get 2 support workers for odd hours when required.
- Identified potential solutions
    - Someone in the role of local coordinator to support families identifying and accessing solutions
    - Enabling families to collaborate to share support staff
    - Help with recruitment and supervision of support staff
    - Providing access to training for parent carers and support workers
    - Finding "Leader Parents" who can provide support and advice to others
    - Set up shared social and sporting opportunities to prepare children to try mainstream ones
    - Allow parents to pay themselves to manage the budget rather than pay for brokerage, (or alternatively to pay for cleaner or equivalent to enable them to spend time managing the budget)
    - Linking young people with other young people who share the same interests, peer support or buddying
- Communication and information
    - Provide a secure way of networking online with other parents and families
    - Send out newsletters to keep parents informed and to share ideas
    - Encourage families to share ideas, information about services/activities and evaluations
    - Enable families to organise events or share support workers
    - Find and share ways of being outcome focussed and celebrate progress towards outcomes, such as a diary for child
- Paperwork
    - Provide clarity in terms of how an SDS budget can be used
    - Different options for and levels of brokerage support to be available
    - Good guidance and useful examples/templates for recruitment and becoming an employer
    - Ideas for personalised and interesting ways of collecting evidence of outcomes

Lessons Learned

Offering families £200 as a means of trying to generate creative thinking about progress toward outcomes was effective. It is a fairly inexpensive ways of letting the family and key worker test out new ideas safely without the family being committed to one or other option for an SDS budget.

The use of case studies in the development of the Resource Allocation System was invaluable, but with hindsight more care about the information asked for at the start would have made this more effective. The case studies should be identifiable and the current service the child and family receive be known, in order to make sense of the exercise.

The spread sheet, by allowing the weighting of scores to be changed, is very useful and as the RAS goes in to use it may be evident that some of the weighting needs adjusted once tested on the ground with a wider range of cases.

Training will be required to ensure that Key Workers are using the Guidance and RAS in an equitable way. Currently there is not consistency between all Key Workers in terms of scoring, suggesting differences in the interpretation of the guidance for the RAS.

The final guidance is hopefully complete while complete, however the information on the back page is generic and incomplete. It is hoped that online information will become available to families in the long term. In-house or voluntary information services, such as CHIP +, could have a role in ensuring the information is regularly updated.

Development of suitable secure online forums for information on opportunities and services, connecting with others, sharing ideas, getting support in managing an SDS budget, sharing staff, planning events, evaluating services and many more will be essential; people cannot make choices or have control without knowing what is available to choose from and being equipped to take control.

Many parent carers have suggested that in the initial stages, some sort of local coordinator who can connect families with one another, know of opportunities in the local area and be able to support families moving on to SDS may be useful. In the longer term, this may be a role that "lead" families would wish to take on themselves.

Decisions still to be reached by the implementation group:

1. Different levels of sign off for indicative budgets, including setting up a board to decide high level cases
2. How to manage overall spend if a budget is allocated to a significant number of families who are currently not receiving the service to which they are entitled
3. How to manage those cases where the indicative budget is significantly different to the current budget
4. How to score family and community outcomes for families with more than one child entitled to an SDS budget
5. Who will review the weighting system and the amount of pounds per point over time

One of the parents from the first trial and now pilot, has developed a journal for capturing plans, achievements and progress toward outcomes. This book, "My Journey", is available from the parent, who will customize for the child and print for a small fee.

Alexander horse riding
2nd Newsletter
Appendix 9

Conclusion

"Last year anything different would have brought a response of 'No, we can't do that'. This year it is more a case of 'Anything is possible with a positive attitude!'" Fiona

Overall the process of development of documentation for Self-Directed Support for Children's Disability Service in Highland has been demonstrably built on participation, with a growing number of families, professionals and service providers involved as the work progressed. The £200 trial for families to get the idea of using the money in creative ways to help their child make progress towards outcomes has worked well. It also opened the eyes of Key Workers and senior managers to the potential benefits of SDS.

The case study exercise and the close working of a small team between finance, CDS and IPP enabled the RAS to be tried, tweaked and tried again until it was possible to make sense of the indicative budgets being arrived at. The spreadsheet set-up will allow CDS to change the weighting of scores or the amount of pounds per point easily. The flexibility of the spreadsheet allows any change to be seen across the caseload to ensure it remains as fair as possible. This also allows the current budget/service demands across the caseload to be easily accessible.

The most important conclusion is evidenced in the stories of some of the families who took part in the first trial and later pilot (Appendix 10). Family life has, in some cases, been transformed. Children are making progress towards outcomes in ways the family had not dreamed would be possible, and parents and siblings have also benefitted from the changes. Choice and control have empowered these families to build on their "real wealth" and deliver better outcomes for the whole family.

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Appendices

Appendix 1	Initial RAS
Appendix 2	Final RAS - Section 8 of Child's Plan
Appendix 3	Final version of guidance
Appendix 4	Final version of score weighting in spreadsheet
Appendix 5	Final RAS spreadsheet for on-going use
Appendix 6	Evaluation report and Newsletter from Taking the First Steps trial
Appendix 7	Information and consent for second phase of Taking the First Steps trial
Appendix 8	Evaluation form for pilot families re SDS
Appendix 9	Information and consent second trial October 2013
Appendix 10	Newsletter from second trial October 2013

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- Children's Disability Service – area managers and case holders
- Children and Families Team in first trial
- Service providers and other professionals
- Steve Macgregor and George McCaig for Child's Plan and Care First IT support

Stepping Out

A second group of families try out a budget of £200 to help make progress toward identified outcomes

& Next Steps

Families from the original Taking the First Steps trial move on to evaluate self-directed support in the longer term.

Stepping out: Calendar Control

Peter suffers anxiety if he does not know what is happening, when and with whom, so repeatedly asks about what is coming up. Peter's money was used to buy a tablet with a clear visual timetable. The family also looked at ASD and ADHD websites for other apps which might help Peter with his learning and social skills. The family chose a Samsung Galaxy 3 and Peter is now able to know what is happening, how many sleeps away and who will be there. The visual timetable works well for Peter, his anxiety is reduced and he is learning some new words too. The tablet is something he has ownership of and he is learning to take good care of it.

Stepping out:
Building a friendship

Timothy enjoyed the opportunity to spend time and do supervised activities with a friend from school. This enabled them to have fun together, communicate and make friends. The support meant that both Timothy and Alan had the time and freedom outside of the school environment to connect and do things they would not normally do.

"During the October holidays, I spent two really fun days doing various activities with my friend Alan. We both go the Charleston Academy and that is how we met." Timothy

Stepping out: Independent Travelling

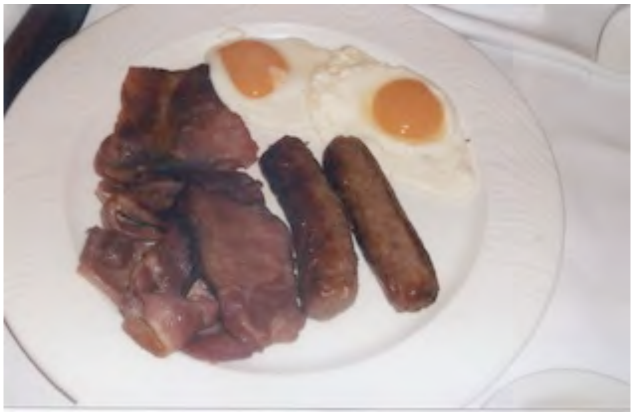
Matthew (16) had been talking about his goal for some time. He wanted to become more independent by accessing the local bus service without a carer. This required both staged and concentrated practice and extra support in the form of back up travel following the bus and activities at each destination. During the October school break Matthew travelled on the bus 1-2 times every day for 7 days in a row. For safety, someone needed to follow the bus in a car and meet him at his bus stop during the first few journeys. He went out for lunch, sport activities, visits to family and shopping and then he took the return bus journey by himself. The trial budget was used to cover extra fuel costs for parents and support staff, staff hours, activities and bus tickets. Despite Matthew's intense phobia of crying babies he was determined to achieve his goal and with this extra support (and a set of noise cancelling headphones) he was able to succeed.

Katie's Grand Days Out

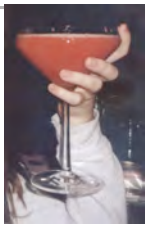
"We thought we would try out some new experiences and things Katie hadn't done since she was a little girl. I thought a spa day would be a very grown up thing to do but I had to phone a lot of places before I found facility that could support Katie's needs and more importantly be welcoming and unfazed by all the logistical maneuvers and questions I had to ask.

"One of Katie's favorite places to go in town is the railway station; she likes to hear the whistle blow and the trains leave the station. So she was very excited when I asked her if she would like to go for a ride on a train with Alix one of Katie's carers. The girls planned a nice day trip to Nairn. Katie loved it on the train and when they arrived they took a walk along the promenade and then into town where Katie had her hands massaged and her nails done at a nail bar, a quick coffee then back on the train home."

Stepping out: Coping with changes at home



Princess for a weekend



Catriona's brother was going away over the October holidays. He was taking his first trip away on his own, an important step for him, but one that his sister would not be able to understand. The family decided to plan a special trip to a hotel in Aberdeen so that Catriona could have her own treat and go to Codonas. Catriona finds new things a challenge and struggles to cope with both the start and the end of an activity. There were lots of opportunities to help Catriona to practice this and the family planned how to timetable activities so that Catriona could cope. Mind you, Catriona's Mum had to keep on trying until she was able to win the fluffy toy, requiring 12 attempts! The hotel, Ardoc House, were wonderful and treated Catriona as the princess she felt herself to be over the weekend, with room service breakfast in bed and (non-alcoholic) cocktails. The trip was a success both in terms of distracting Catriona from her brother's absence and in helping her to anticipate both the start and the end of an activity and cope with this without distress.

Another Big Brother leaves

Alex's big brother was leaving home to join the armed forces. This was a huge transition for Alex. The school was very supportive and, working with the family, developed a social story for Alex. Alex's brother would be away for six weeks for his initial training and then there would be a passing in parade to which the family was invited. The family chose to use the money to take Alex to the passing in parade so that he could see where his brother was, what he was doing and hopefully gain understanding about why his brother was no longer living at home. Although planning such a trip was a real challenge, Alex and his family managed to go. This difficult transition was made more manageable for Alex.

Stepping out: Getting fitter

Two young men on our trial, John Angus and Mark, each wanted to lose weight and become fitter. Mark wanted to get fit and lose weight at home before engaging with others in sport or activity. Mark managed to purchase several pieces of gym equipment with his money by buying them second hand. He now starts and finishes his day working out and even does so while watching TV.

John Angus has joined a gym and is going there regularly now. An activity he wanted to do was archery, and over the holidays he took part in a competition and won gold! John Angus also wants to learn to cook and made a meal for his Granny.

Stepping out: Trying something new

The desired outcomes for Bobby were for him to try new activities outside of the house and to engage with other young people. A young student was found as a drumming instructor. Bobby, equipped with ear defenders, took up drumming. He was able to relate and engage with another young person as well as try a new and different activity.

Fired on by his success, Bobby went on to try cycling at a 1km off-road track, which is designed for all cyclists as well as people with additional physical and support needs. Bobby was able to engage with the young organiser and return regularly to improve his time.

"Out of all the term time holidays, the October break was definitely the most productive and most enjoyable for Joseph. The activities he participated in involved things he had never tried before and places he/we had never been. The money we were granted allowed him and us to have a no holds barred activity filled 2 weeks. We noticed a more interested and confident child throughout the 2 weeks and we were very proud of how he adapted to new places and people (first time at SOAR). The ease of the holidays (with so much to do) made it fly by, and created a much happier environment, rather than the sometimes frustrated and stressful days where Joseph didn't have as much to keep him entertained!" Jodie, Joseph's Mum

Alice is a young lady who wanted to use her money to access a course on a subject of interest to her. She initially booked a course in the central belt, but as the time approached to go, felt a bit daunted. Alice was able to get her money back and instead found a local course, which she attended and enjoyed. The local course can be followed up by a further course and may even lead to a qualification in the future.

Dylan was able to attend "Relax Kids" sessions at Millburn School, which have been a great success. The activities are designed for children with autism spectrum conditions. Dylan is able to be energetic in some activities but then is enabled to relax at the end of the session.

Josh managed to do s horse riding and a gondola ride. The family had hoped to find an activity to meet the very different needs of both sons, but that was not achieved this time.

Stepping out: Connecting with others

I liked my brother playing nice with me. Miah

Miah. Thank you

Brotherly and Sisterly Love

Leo does not always find it easy to play along beside his sister. It is hard for the family to find things to do which they can enjoy together.

The family planned to go to Edinburgh Zoo for a day in the holidays. Granny was also invited along. The day was a great success and the picture is evidence that brotherly and sisterly love thrived that day.

"Thank you for the fantastic day. It was great to see my kids getting along so well and Leo to be going up and having the confidence to pay for something himself. Was a happy day for all." Sarah, Leo's Mum.

Nicole loves animals and a family day out to the wildlife park was planned to celebrate her birthday. All had a lovely time. Another day it was arranged for Nicole to have a session at a local soft play area with some of her friends.

The family has found it difficult to find someone they know and can trust to look after Nicole so that she can take part in activities independent of her family. Close family friends have a teenage daughter, Naomi, so beloved by Nicole that she calls her "Big Sister". Naomi was able to take Nicole out on a few trips to swimming and other activities. This was a great success.

Activities with friends and cousins

Anna's Mum took time off work to be with Anna over the holidays and made plans for Anna to link up with family and friends. Anna is a gregarious wee girl and loves to spend time with others.

Anna had a lovely day with her cousins and friend at the swimming pool, followed by lunch. On another occasion, Nicole went horse-riding with two friends.

Next Steps for the Cameron Family

Next Steps: Progress after the £200 trial

The Cameron family have been transformed. The parents look different, say they feel different and have begun to take up individual interests again. What has happened to bring about this change? The family moved on to an SDS budget after the Taking the First Steps trial in summer 2012.

The Cameron family have a teenage son, Gregor, who has profound autism. They also have two teenage girls. Gregor's needs were such that family life needed to be organised around him. Due to Gregor's epilepsy and poor sleep patterns; he slept on a mattress in his parents' room, meaning none of them got much sleep. Gregor's behaviour could be unpredictable, and this limited what the family could do or where they could go. Gregor did and still does go to the Orchard monthly and attend Drummond School, with his parents making the 60 mile round trip twice a day to take and collect him.

So how has an SDS budget transformed their lives? In the first instance the family purchased a caravan. This is set up with all the things that are important to Gregor so it is somewhere he can feel relaxed. The family have found a caravan site where they are always made welcome and whose owners have shown understanding towards Gregor's needs. They get the same spot, or as close to it as possible, each time they come. This is near the park where Gregor spends many a contented hour. With Gregor settled, the family have room to do things for themselves. Having the caravan means that if Gregor gets frustrated at home, the family can decide there and then to go off in the caravan and Gregor is able to calm down and enjoy himself.

The family also purchased a double bed for Gregor where he sleeps better and which provides a safe place if he does have a seizure in the night. This has improved everyone's sleep patterns. Gregor now has a trike, which enables his parents to take him out around the community. The garden has been made safe with high fencing and bark chipping and Gregor has space to keep and play with his collection of shells and stones from his caravanning holidays. Other young people can come and play with Gregor here, a big move forward for him.

The family have been trying to get a support worker closer to Gregor's age to take him out on activities. However, they have been frustrated by car insurance rules. The family use mobility allowance for the 120 miles round trip to school and this exceeds the maximum miles for mobility "any-driver" insurance. It is expensive to add younger drivers to the insurance they have.

Now the Cameron family have seen the benefits of taking an outcome focus to planning, they have developed a plan to help expand Gregor's diet to ensure he eats proper meals. Gregor is well on his way to new eating habits, starting with soup!

The Cameron family are friendly with another family who have a child with additional support needs. When this family also access an SDS budget the two families plan to work together to maximise the benefit to both families.

Next Steps: Progress after the £200 trial

Next Steps for the Milligan Family

Alexander is a five year old with complex health needs, epilepsy and profound autism. He is not able to express himself and his lack of understanding of his own or other's safety means that he requires moment-by-moment supervision throughout his waking hours, and he does not sleep consistently. Alexander has an older sister and a younger brother, his family live in a remote rural location.

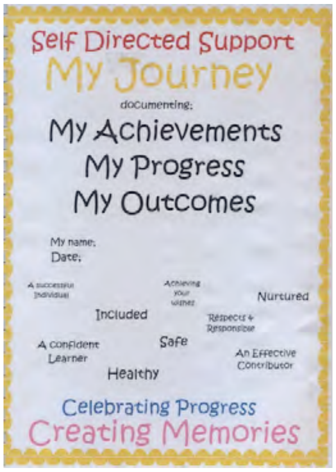
Before Self-Directed Support (SDS) the family were close to crisis. Alexander requires constant supervision, which meant the other children missed out on attention at home and were unable to attend activities outside of the home. Without regular sleep or ability to relax during the day, the family were struggling. For example, when Alexander's mother is the only adult at home, she cannot go to the toilet without leaving the door open so that she can continue to supervise Alexander.

The family took part in the Taking the First Steps Summer 2012 trial for SDS. Although there were difficulties initially in getting suitable support workers, due to the rurality of the family and the complexity of Alexander's needs, the family now has several support workers who can take Alexander after school and for a while on Saturdays. These support workers have mainly been recruited from the special needs school and play scheme, which Alexander attends.

The transformation this support his brought to the family is amazing. Alexander is now able to access weekly swimming, horse riding for the disabled and music therapy sessions, which he loves. Alexander's older sister is now able to attend the normal out of school activities her friends go to, such as swimming club. Both of Alexander's siblings can now get some attention and time with their parents. His older sister had been displaying some challenging behaviour but being able to do regular things with her peers and family have transformed her.

It has not always been made clear what the SDS budget can or cannot be spent on. Sometimes it seems it can only be used for support worker hours for Alexander, although when Alexander's mother has to take him to medical appointments away from home, it is the other children who require child minding. The family have been able to argue a case for some pieces of equipment such as an all-terrain buggy, but not for other equipment such as a monitor, which would enable the parents to be reassured that they would hear if Alexander was having a seizure during the night. A suggested list of things that could or could not be purchased with SDS monies would be helpful; although such a list could not be comprehensive, it would provide guidelines about the sorts of things that are allowed.

Good ideas for sharing:



Self Directed Support
My Journey
documenting:
My Achievements
My Progress
My Outcomes

My name:
Date:

A successful Individual
Achieving your wishes
Nurtured
Included
Respected + Responsible
A confident Learner
Safe
An Effective Contributor
Healthy

Celebrating Progress
Creating Memories

One of the parents from the first trial and now pilot scheme, has developed a journal for capturing achievements and progress toward outcomes.

This book "My Journey" is available from the parent, who will customize for the child and print for a small fee.

always remember:
YOU are BRAVER THAN YOU BELIEVE
STRONGER THAN YOU SEEM and
SMARTER THAN YOU THINK: a.a.milne

YOU CAN DO ANYTHING

Calling parents or service providers:

Many parents have indicated that there are welcome benefits from the choice and flexibility of Self-Directed Support, but find the thought of the paperwork and employer's liability daunting.

There are services that offer to do pay roll for a fee, but there might be advantage in a service that can also offer support with recruitment, training and other human resource issues, which will be needed to ensure quality of service.

It may be that current voluntary sector organisations develop an additional service to meet this need. It may be that parent carers with experience could offer this service to other parents, thereby using their experience to earn a little money themselves. Or it may be someone sees the opportunity for a brand new service and develops a service to meet the need.

Another key point parent carers have shared, is the need for information and ideas about what is out there to do and how to access it. It may be that parents also want to recommend to other parents places, which are particularly accommodating.

In each area of Highland there are Link Up Lunches, organised by Health and Happiness where people from a local area can come together and exchange ideas. If you would like to network with others to develop services in your area, this might be a good place to start.

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