

CABINET ITEM COVERING SHEET PROFORMA

AGENDA ITEM

REPORT TO CABINET

DATE 26th November 2009

**REPORT OF CORPORATE
MANAGEMENT TEAM**

CABINET DECISION

Portfolio – Lead Cabinet Member – Councillor Ann McCoy

TITLE: PERSONALISATION UPDATE AND THE INDIVIDUAL BUDGET DELIVERY POLICY

1. Summary

This report provides an update on progress in Stockton-on-Tees for the transformation of adult social care services in line with the direction of travel required by the 'Putting People First' concordat. The process of offering individuals requiring social care services a Personal Budget is explained in the accompanying 'Individual Budget Delivery Policy'. Work has progressed on the development of a Resource Allocation System and Self Assessment Questionnaire, which will enable people to self-direct their support by offered an upfront budget allocation and supporting them to complete a costed support plan explaining how they wish to receive support services in future. This new process will impact positively on our ability to manage social care assessments and meet new performance targets.

2. Recommendations

1. To note the direction of travel, support the project actions and the principles of personalising social care and in particular to approve the adoption of the common Resource Allocation System (RAS) and the Personal Needs Questionnaire (PNQ).
2. To approve the Individual Budget Delivery Policy and to keep the policy under review and amend as required following implementation.

3. Reasons for the Recommendations/Decision(s)

To enable Stockton-on-Tees Borough Council to meet the timetable for the transformation of Adult Social Care services in line with Putting People First.

To ensure there are clear pathways for the delivery of self directed support services across all social work teams.

To ensure 15% of social care clients receive self directed support by March 2010 and 30% by March 2011 in line with the performance target NI 130.

4. Members' Interests

Members (including co-opted Members with voting rights) should consider whether they have a personal interest in the item as defined in the Council's code of conduct (**paragraph 8**) and, if so, declare the existence and nature of that interest in accordance with paragraph 9 of the code.

Where a Member regards him/herself as having a personal interest in the item, he/she must then consider whether that interest is one which a member of the public, with knowledge of the relevant facts, would reasonably regard as so significant that it is likely to

prejudice the Member's judgement of the public interest (**paragraphs 10 and 11 of the code of conduct**).

A Member with a prejudicial interest in any matter must withdraw from the room where the meeting considering the business is being held -

- in a case where the Member is attending a meeting (including a meeting of a select committee) but only for the purpose of making representations, answering questions or giving evidence, provided the public are also allowed to attend the meeting for the same purpose whether under statutory right or otherwise, immediately after making representations, answering questions or giving evidence as the case may be;
- in any other case, whenever it becomes apparent that the business is being considered at the meeting;

and must not exercise executive functions in relation to the matter and not seek improperly to influence the decision about the matter (**paragraph 12 of the Code**).

Further to the above, it should be noted that any Member attending a meeting of Cabinet, Select Committee etc; whether or not they are a Member of the Cabinet or Select Committee concerned, must declare any personal interest which they have in the business being considered at the meeting (unless the interest arises solely from the Member's membership of, or position of control or management on any other body to which the Member was appointed or nominated by the Council, or on any other body exercising functions of a public nature, when the interest only needs to be declared if and when the Member speaks on the matter), and if their interest is prejudicial, they must also leave the meeting room, subject to and in accordance with the provisions referred to above.

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RECOMMENDATIONS

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DETAIL

1. 'Putting People First – A shared vision and commitment to the transformation of Adult Social Care' was published as a Government protocol in December 2007. The Government stated that 'Putting People First 'sets the direction for adult social care over the next 10 years and more'. It confirmed the approach to 'Personalisation' and 'self-directed support' as a follow on from the existing Direct Payments legislation in place since 1996.
2. Self-directed support means that people are able to design the support or care arrangements that best suit their specific needs. LAC (DH) (2008) 1 *Transforming social care* states that "In the future, all individuals eligible for publicly-funded adult social care will have a personal budget (other than in circumstances where people require emergency access to provision); a clear, upfront allocation of funding to enable them to make informed choices about how best to meet their needs, including their broader health and well-being".
3. Local authorities already have powers to make direct payments under the Community Care, Services for Carers and Children's Services (Direct Payments)(England) Regulations 2003 and the Government is considering extending this through corresponding powers and duties for the NHS to make individual budget payments, as part of the DH pilot work on personal health budgets. Circular LAC(DH)(2009)1:Transforming Adult Social Care, published on 5th March 2009, sets out further information to support Councils and their partners in this process and this indicated that a Green Paper would be published by the Department of Health this year. This

Green Paper '*Shaping the Future of Care Together*' was published in July 2009 and set out a vision for a new care and support system.

4. The Care Quality Commission in their recent annual review of performance of the Council, which will be officially published on 2nd December 2009 have highlighted that the Council is only adequately performing under the outcome relating to increased choice and control. This is because it does not yet have in place self directed services or individual budgets. The systems for putting these in place have now been developed. We need to begin to offer self-directed support options to clients this year if we are to improve this outcome rating.

Key elements of required changes

5. The seven main elements of the project work undertaken to develop a new model for the delivery of adult social care services are:
 - Developing a local **Resource Allocation System (RAS)** to support financial modeling for the delivery of personal budgets and building on the learning from care assessments and service delivery. This is a points based system, with a differing price per point to recognise cost differences. We have used two separate models to develop our local RAS with 100 and 300 service user records being analysed to give 90% and 94% accuracy levels. It supports work ongoing to develop a national common assessment system promoted by ADASS and collaboratively developed by 18 LA's across the country in line with similar models for nationally influenced funding such as Revenue Support Grant, Dedicated Schools Grant and Housing Benefits.
 - Developing a local **Self-Assessment Questionnaire (SAQ)** to support the assessment of a client's own needs through the self-directed support model. Agreement has been reached locally to name this a Personal Needs Questionnaire (PNQ). We have used a model developed locally by Hartlepool BC and the 'in Control' organisation and adapted to meet local needs. By completing a PNQ this will allow a **personal budget** for every individual that has been calculated using a clear and straightforward system. This is an assessment process that makes sure a client is in control and able to express how that individual wants to live their life.
 - Improving the process of **access to our services**, through **better information and advice**. Seeking to identify all available services for adults in one place and keeping this information up to date through the development of a new website. Seeking to resolve queries in a more responsive way, either to signpost to other, more relevant avenues of help (e.g. voluntary services), provide low level services (e.g. equipment, community meals), or to progress to a more detailed assessment of need or emergency service. There are opportunities here to link with services such as voluntary organisations and health for example.
 - Providing a **support planning and brokerage framework** to support and assist people in choosing support services; Seeking to develop new models of support through co-production training with users of Direct Payments (DH pilot toolkit) and developing training in support planning for in-house staff and provider organisations so that a range of options can be explored with clients on how this personal budget is managed, from the individual themselves, to the Local Authority on their behalf. We are now considering a brokerage process whereby the best deal can be found for the use of a personal budget, with staff who can provide detailed information and knowledge of the range of services on offer.
 - Understanding the current **care and support pathways** and developing new systems to ensure clear and simple pathways to support encouraging more influence and control for the individual through personal budgets. We have appointed a Pathways Project Officer to developed the programme of work and a pathways sub-group to test out the new policy and procedural guidance. This work included the development of the Individual Budget Delivery Policy.

- Working with **existing and new providers** to develop flexible and responsive care and support services. Ensuring the range of services that are wanted by our citizens, are available to buy. Ensuring these services are appropriate, good quality, provide value for money, and are safe. We have undertaken a number of information giving events with current providers and have advised new social enterprise organisations on potential requirements. This work continues as we develop further information for the 3rd sector, a Future Jobs bid and business development opportunities. It is expected that new and existing organisations will grow their business around the opportunities of self-directed support once people take up the offer of a personal budget.
- Developing the **workforce and skills** for the future. The national social care workforce strategy was published in April 2009 and closely followed by the launch of the North East England regional workforce strategy in June 2009 following an extended period of consultation. This has proposals to ensure the **workforce** and staff working for statutory and independent care providers have the right level of skill and knowledge to deliver this new model of care to our citizens. We are currently developing a local action plan through the workforce sub-group.

Local developments

6. A programme for 'Putting People First' and Personalisation in Stockton-on-Tees was established in the summer of 2008 and explained in a report to Cabinet in July 2008, which described the collaborative approach being established between central and local government, the sector's professional leadership, providers and the regulator. The report also highlighted how Children, Education and Social Care were planning to take forward the development of new systems and processes to ensure appropriate safeguards were put in place to protect vulnerable adults and ensure no financial abuse.
7. Since then a project manager has been appointed (October 2008) to work with a project board, using a project plan to agree and drive forward the project requirements. The personalisation programme has involved work across seven main areas to develop proposals for achieving personalisation of adult social care services. These areas are based on helping people who use social care services, families and their carers by;
 - Developing a local Resource Allocation System (RAS);
 - Developing a local Self-Assessment Questionnaire (SAQ) known as the Personal Needs Questionnaire (PNQ);
 - Improving ways to gain access to information and services;
 - Providing a support planning and brokerage framework to support and assist people in choosing support services;
 - Understanding the current care and support pathways and developing new systems to ensure clear and simple pathways to support individuals with personal budgets;
 - Working with existing and new providers to develop flexible and responsive care and support services;
 - Developing the workforce and skills for the future.
8. The Personalisation Project Board is chaired by the Corporate Director of Children, Education and Social Care and involves senior representatives from across the Council and PCT. The Personalisation Project Board has considered the key objectives of the main elements of the Personalisation programme through its project plan. The Board maintains overall control of the workstreams and actions to enable wider engagement. A number of events and meetings have been held with elected members, senior managers, other agencies, providers, carers and focus groups of people using services to raise awareness and help in opening up discussion around the ideas and features of the future model for personalisation of social care services.
9. Work in each area has progressed with project sub-groups being formed to drive forward the required changes. Options for each area have been developed from local, regional and national sources so that best practice and effectiveness could be identified. This work has resulted in a set of proposals that are now being brought together as a proposed 'operating

model' through the development of an Individual Budget Delivery Policy. This policy has been developed to underpin the various means of delivering resources to individuals and carers as part of the Stockton-on-Tees Borough Council Adult Social Care Personalisation programme.

The next steps

10. The proposed model for the future is described in the attached document 'Individual Budget Delivery Policy', which has recently been consulted on. At this stage, the policy covers the main elements of delivering self directed support using a personal budget, through an up front allocation of funding. In line with work going on in other local authorities the processes are evolving and will be subject to ongoing review. For example ADASS have just launched a new national Resource Allocation System and this will be used as a tool we use to deliver self directed support in future. In addition the Council is procuring a new adult case management system (IT system) to replace the existing record management system, which will ensure compliance with the developing self directed support system.
11. Subject to approval of the 'Individual Budget Delivery Policy' it is intended that the revised model for personalised services will be brought into effect in December 2009. Following a period of settling in the next phase of the project work will test out our initial findings based on outcomes for clients and performance improvements. In view of the scale and complexity of the changes impacting on social work teams over the next 18 months the project management approach will remain in place to ensure appropriate training, support and policy development is maintained. There will be required revisions to information and case management arrangements, changes in the processes that we operate including financial systems, new brokerage roles will need to be developed and internal and external service providers will need to be supported so they can operate in more flexible ways according to the preferences and choices of individual service users.
12. The implementation programme will involve extensive discussion with service users, staff and others who will be affected by the changes. Our aim will be to ensure that there is a smooth transition to the new operating model and to the changes required to achieve this such as redefining roles and providing appropriate training and skills for staff.
13. Development work with existing and new providers is a key part of the Personalisation programme. A number of local information events have already been held with existing provider organisations (providers from domiciliary care, residential care and supported housing) and with potential new providers from the 3rd sector (through Catalyst) and with social enterprise organisations. In addition the North East England Joint Improvement Partnership (JIP) and Improvement and Efficiency Partnership (RIEP) have regional projects focusing on market development including 'Electronic Marketplace for social care', 'Accessible Transport', 'Quality Standards in non-regulated and regulated services', 'Provider Development' (through a Festival of Ideas event) and 'Market Development via User Led Organisations'.
14. In parallel with the Personalisation programme for social care, there are corresponding developments being pursued in other linked services, such as supported housing (through a review of Supporting People contracts) and the NHS (through the development of the Personal Health Budgets pilot). We are working to ensure that effective links are made so that each person can have the right services in place according to their individual needs and choices. Some examples of these links are for personal health budgets; promoting preventative services and enablement in social care and health; and supported housing so that people can continue to live in the community as an alternative to residential care i.e. in Extra Care schemes.

Additional information

15. Details of Stockton's current unit costs of services will be made available (to be tabled). It is hoped that by introducing a self directed support process, individuals will gain opportunities for more choice and control and the Council potential financial savings; although this has to be

tempered with the likely increase in take up due to demographic changes (growing older population) and more people finding the system attractive due to the choices available. (See also Paragraph 20)

16. An example of a Personal Budget arrangement would be: An individual currently attending 'day care' three days per week is taken through the self directed support process at the annual review stage. They complete the Personal Needs Questionnaire with assistance from the social care Practitioner with the involvement of the carer. They are then made aware of their 'indicative budget'. The person chooses to continue receiving the 'day care' support on two days (this is given under existing arrangements) and, using a Direct Payment, decides to spend their 'budget' on employing a personal assistant for three hours per week to take them to a regular weekly evening 'pottery class'. The costs of the personal assistant and travel are less than the cost of the additional day at the 'day care' centre. The improvement in quality of life for the individual and their carer is greatly valued.
17. Some additional case studies are included by way of example to show how Direct Payments and Personal Budgets have helped people to self direct their support in other local authority areas and what they have done differently with the money allocated to meet their needs (Appendix 1).

FINANCIAL IMPLICATIONS

18. One of the outcomes of the Personalisation process is likely to be a redistribution of budgets and a change in emphasis; from accounts held to pay for total costs of care provision e.g. home care, to accounts which will now be specific to each individual client and may result in more people opting for Direct Payments. Many authorities, including Stockton-on-Tees are looking at a Resource Allocation System that is designed to allocate resources to individual clients based on an assessment of their needs and/or required outcomes. This is a model developed locally and now being taken forward by ADASS in the development of a national common RAS system.
19. Offering self directed support through personal budgets requires a review of our current system of client contributions. This work has been undertaken and it is envisaged that we will not have to change the current system. We will continue to use a system to allocate budgets to service users *net* of client income, significantly reducing the need for invoicing in the long-term. Current charging mechanisms are informed by the cost of provision e.g. day care costs, etc. Initial guidance from Department of Health has suggested that charging may be based upon a fixed proportion of the costs of service provision, subject to both Local Authority cap on maximum charge and clients' maximum affordability, identified through a financial assessment process.
20. Following implementation, there is the *potential* for a certain level of ongoing efficiency to be generated through service users directly procuring their own care packages and having the flexibility to purchase care specific to them at locally agreed prices. It is however far too early both locally and nationally, to gauge whether efficiencies are actually realisable or not. There are numerous other factors to consider, not least of which is an anticipated increased level of demand from clients who previously may not have considered a package of care.
21. In order to support the costs of implementation, the Department of Health has awarded the Council a specific Social Care Reform Grant allocation of £289k for 2008/09 with further grant of £677k being receivable in 2009/10 and further grant of £838k receivable in 2010/11. The total costs of implementation will be contained within this level of resource. The actual financial implications of Personalisation will be closely monitored through robust financial reporting.

LEGAL IMPLICATIONS

22. The Association of Directors of Adult Social Services (ADASS) has, in October 2009, published legal opinion as to why the main tenets of Putting People First can be implemented within the

current legal framework. Meeting the duty of care is being incorporated into the new self directed support system, alongside appropriate safeguarding arrangements.

23. There are therefore no direct legal changes associated with the delivery of 'Putting People First' and self directed support. The introduction of a self assessment approach still requires a formal assessment of need under the powers of the National Health Service and Community Care Act (1990) and required by the Assessment Directions (2004). In addition Direct Payments have existed since 1996. The new arrangements help with the delivery of good practice under existing legislation, based on involving users and carers in the assessment process.

RISK ASSESSMENT

24. The opportunities and risks associated with the introduction of new approaches to achieve personalisation have been identified and assessed. Major changes always result in unavoidable risks but the alternative of avoiding change will lead to even greater risks if services and our approach become out-dated. The changes in adult social care services through 'Putting People First' and the project management arrangements will ensure that risks are minimized.

25. The key risks identified and mitigating factors are:

- Budgetary pressures based on miscalculating the Resource Allocation System – mitigated by testing of the model using samples of 100 and 300 clients. This is estimated to achieve a 90% and 94% accuracy rate. Budgetary pressures will be monitored closely in the initial stages of implementation. A contingency of between 10% - 20% will be top sliced from the RAS allocation to allow some flexibility in the indicative budget allocation and to assist with overall budget management. The strong focus on effective financial management in place will continue and be adapted to meet the new self directed support arrangements.
- Budgetary pressures from an increasing number of clients using the self directed support process. The uptake of self directed support packages would be carefully monitored. The RAS will be reviewed on an annual basis and appropriate adjustments made.
- Budgetary pressures from people misusing their allocated budget (through a Direct Payment) and requiring unmet needs to be met by the Council. The offer of a Direct Payment will be based on a risk assessment (as it is currently) and careful monitoring of the support plan. Withdrawal of the Direct Payment is possible if concerns are identified.
- The potential for people to stop using existing in-house services. The impact on existing in-house services will be monitored as people are expected to make alternative support choices over time. It is expected that the majority of older people already in the social care system will choose to receive existing services in line with observations of other local authorities, however this is expected to change in future years as more and more new clients enter the system.

COMMUNITY STRATEGY IMPLICATIONS

26. The personalisation agenda contributes to the well being of adults and links with the health and well being and older adults priority themes.

EQUALITIES IMPACT ASSESSMENT

27. The Personalisation and Self Directed Support arrangements have been subject to a comprehensive equality impact assessment. The overall impact of the Personalisation policy framework is considered to be positive with an impact score of 77 / 105.

CONSULTATION INCLUDING WARD/COUNCILLORS

28. The changes in adult social care services through the 'Putting People First' programme require consultation at each key stage. As part of the developing programme we have held

consultation events with Members, in-house staff, provider organisations, carers, and focus groups with people with mental health problems and people with learning disabilities, alongside information giving at the Over 50's Assembly and through parent support groups. Further consultation will be held throughout the implementation of the programme over the next 18 months.

29. The Individual Budget Delivery Policy is currently going through a process of consultation with in-house staff groups; the current Direct Payments support organisation; carer support organisations and providers of care and support services operating in Stockton-on-Tees such as MIND and Age Concern.

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Background Papers

Key documents that can be referred to for background information:

- "Our health, our care, our say: a new direction for community services", Department of Health, January 2006
- "Putting People First" Concordat, Department of Health, December 2007
- "Transforming Adult Social Care LAC (DH) (2008)1", Department of Health, January 2008
- "The case for change – Why England needs a new care and support system", HM Government, May 2008
- SBC Cabinet Report 'Personalisation of Services – update', 17th July 2008
- "Transforming Adult Social Care LAC (DH) (2009)1", Department of Health, March 2009
- Shaping the Future of Care Together – Green Paper (DH) July 2009
- Personalisation and the Law: Implementing Putting People First in the current legal framework (ADASS), October 2009

Ward(s) and Ward Councillors:

Borough wide implications for all Wards and Ward Councillors

Property

None

APPENDIX 1

Personalisation – What difference will Personal Budgets make?

In two local authorities where Personal Budgets have been on offer for 12 months, clients of day care centres (learning disabilities) have been choosing to do other things with the money allocated to meet their needs. The following is a list of “things” people have chosen to do with their Personal Budget (in order of likelihood).

1. Access to Leisure
 - Clubs, societies, hobbies
 - Eating out and going to the pub
 - Health & fitness
 - Museums & galleries
 - Music, cinema, disco, bowling
 - Shopping
 - Visiting family and friends
 - Watching sport
2. Help at home
 - Support to do cleaning, washing, etc.
 - Help with meal preparation
 - Gardening
 - Dog walking
3. Personal Assistant
 - Help with personal tasks i.e. dressing, bathing, etc.
 - Assistance with correspondence
4. Public transport
 - Support to travel on public transport
 - Access to funds to use transport including taxis
 -
5. Friends & family to help
 - Assistance with personal care
 - Help to get out and about
6. Education and training
 - Access to further education courses
7. Carers breaks
 - Funding towards break
8. Holidays
 - Alternative to respite care i.e. holiday breaks
 - Caravan
9. Support with work
 - Personal assistance
10. Day Centre
 - Traditional day care centre provision

APPENDIX 2

Case Studies taken from the in Control website

Barbara's story

Barbara's sister describes how Barbara was able to gain more control despite her deteriorating health.

On the death of my Mother 10 years ago my sister Barbara, who has Downs Syndrome, moved in with me and I became her carer.

Barbara was capable of looking after her personal and everyday needs by herself. She happily attended the Day Centre – something my Mother would never let her do – she managed to make friends and seemed extremely content with life. We were also members of the Special Needs Club attached to our parish and would go on outings and meals with them.

Six years ago I retired and managed to get Barbara into a new Day Centre for three days per week which gave me some spare time to myself. Whilst at this Day Centre Barbara received two certificates for Basic Learning Skills.

About 3 years ago Barbara started showing some changes in her behaviour. She would hide and covet things that were not hers. Post would go missing. This was the onset of her Dementia.

Even with the dementia she continued to attend the Day Centre 3 days per week enjoying the company, cooking, needlework and art.

Miserable and detached

Just around her 60th birthday, Barbara was no longer willing to get on the Community Bus to go to the Day Centre, and did not want to use the toilet and refused to do other things that she would normally do – like going out. I started to take Barbara to the centre in the car. When I collected her in the afternoons I found her miserable and detached from the crowd - where normally she would be in the midst of it all! Having Barbara home all day every day became very restricting for me and to be honest I felt that I would not be able to cope with her and normal family life with my children and grandchildren.

With the help of my Social Worker Barbara not only got the attention of a very good Occupational Therapist, who visited weekly and started projects with her that we and her carers, are continuing today. I was also given a few hours per week respite, which helped me to charge my batteries. My hours were increased to 7 per week again a little extra freedom but not nearly enough when the task in hand is so very demanding.

Then came 'in Control'. I was advised that I was to receive a budget of £23,500 per year. In order to get this money I needed to write an in-depth Support Plan stating exactly who Barbara was, what her needs were and how I was going to use the money. This Support Plan is being updated so that each new carer knows exactly what Barbara needs as she is unable to tell them herself. The full application process took a few months. A long time when the person being cared for is deteriorating quickly and there's no indication of when the budget for extra help is to start.

Far happier

Since 'in Control' has started I have a few hours off each day. I am a far happier person and I feel that because I am more relaxed, in general, my attitude to caring is a far better one, than a few months ago when I began to resent everything I did for my sister. I will also have the ability/freedom to have a few extra hours off once the school holidays come around and be able to spend time with my grandchildren – something I could not do before 'in Control'.

I have covered the additional care initially by using an agency and the Alheimers Society. To get

extra hours I shall, in due course, be employing full time carers. 'In Control' gives one the chance to use various options.

The recording of the budget both income and expenditure is very easy, with returns to be made to The Council and the Independent Living Fund on a monthly basis.

Mrs B's story

How Mrs B's daughter is able to care for her mum.

This story is told by Mrs B's daughter as Mrs B's verbal communication is very limited, but mum agreed to everything that was said.

My mum already had a care package provided by an agency, my mum is 74 years old, fulltime wheelchair user who has had a severe stroke, she has a traditional care package, but was not happy as the agency sent 24 carers in 21 days. This is when the social worker told us about individual budgets. Wendy came and visited and explained the process - mum decided to give it a go because it appeared to be more flexible and we would have more control.

Using a support broker

Mum had help to do a support plan from a support broker; he gave us a lot of information and helped us in other areas as well he certainly knew his stuff.

The broker e-mailed us a support plan template and we did the collating of information ourselves it did not take to many hours but it was just difficult finding the time to do it. The broker collected all the information from us and typed up the support plan for us we were happy with the end result. Mum is using her individual budget to purchase care from an agency. She can purchase 1 hour more a week with an individual budget than she could with traditional services, it has not made too much difference but I think you have more control with an individual budget.

Mum does not like respite but has agreed to have 1 week every 3 months to give her husband a break, this respite is paid for by the Primary Care Trust because she has nursing needs so this does not affect the individual budget..

Mum says, 'my husband says he is happy with me having an individual budget as long as I am happy.'

Cindy's Story

Cindy was happy for others to know about Individualised Budgets as a way of helping people get a better life.

Cindy's hopes before Individualised Budgets were somewhat daunting. She was concerned about having her own responsibility for the allocation. The difficulties that Cindy faces include having a visual impairment. Cindy lives a busy and challenging life with her three children and her husband. Despite her own difficulties Cindy runs the home, does housework, shopping, and takes the children to and from school.

Before her Individualised Budget, Cindy had a direct payment but she had no idea how many hours she was receiving. Because she did not have a plan, the payments were not helping her with the things that mattered in her life.

"I found out originally about Individualised Budgets through Social Services. It started with the whole process being explained to me. Then I was allocated a support broker who came to my house. I found out how much money I would receive. They did a questionnaire with me and worked out from the questionnaire how much money that would come to.

Initial worries

It was worrying at first. I'd have to watch my own money...it frightened me, the thought that I've got to watch my own money and control that! I'd have to write my own plan? I wouldn't have a clue!"

Before the Individualised Budget, Cindy was faced with many restrictions to her support. On one occasion, she was told by the social care agency that she would be unable to receive a direct payment to pay for support to help her attend a local college. Cindy realised that something had to change.

"Until you sit and write a plan and start thinking about what you really want, you're not going to know if everything's all right. I think you should at least look into it. I can honestly say that your life will be improved. So I think it's a really good idea to think about it carefully and not just think, oh no, I couldn't do it - because there's ways that you can use your Individual Budget. You can use your money in ways you never realised."

One of the most important factors in making her individual budget work was having the support of an agency in recruiting PA's. Cindy's P.A. explained:

"I'm employed by the Recruitment Agency and Cindy's one of their clients. Individual Budgets are flexible for me in the sense that sometimes I don't need to come to Cindy the whole day, especially when the kids are not in school, because she takes them out somewhere... So with the school holidays coming up, I don't have to spend the whole day with Cindy. Like today, I'm spending the whole day with her, but during the holiday I would maybe come in the morning and do some stuff around the house and then drop her somewhere with the kids and then that's it."

Now that Cindy is in receipt of an Individualised Budget, she says it has changed her life for herself and her children. There are new hopes for the future. To be able to get further training and find employment in the future is no longer just a dream. The practical help is now there to help Cindy take care of her family and keep her well enough to do so.

Being able to support herself and her family is no longer the frustrating challenge it was in the past. Cindy has many more challenges ahead but they are more like the ordinary ones most people face in life.

Cindy's advice is to go for it, but to get the right support in managing an Individualised Budget. Ask if there are agencies in your area that can help.

Cindy has become a member of her local committee helping others with Individualised Budgets. She has an agency to help manage the finances and keep track of statements. For Cindy this is a way of not worrying about the management of her allocation. Although this is something that she prefers, she also commented that it is a simple process should not be a cause for anxiety.

Maggie's Story

An example of how taking control is so important for older people.

This story was told to a member of 'All of Us', an organisation that develops support plans for older people. At the time of collecting Maggie's story she was in the early stages of taking up her new plan.

The Process towards a better Plan

Before the plan was developed, Maggie had been receiving traditional day support after moving into sheltered accommodation. In her 80's and in need of support because of ill health, she had no idea that there could be different choices in her life.

Maggie was invited to spend a day with 10 other people who were using older peoples' services to learn more about being in control. The experience also enabled her to hear about their

experiences. She became very interested in support plans and how they could help someone lead their own life rather than having to fit in with others. Maggie explained that at first, no one had listened to them, particularly about what life had been like in the past and the difference in their lives today.

In the past, Maggie's experiences of Social Service support had been very negative. Being asked questions about her financial circumstances was a particular concern, too. She wondered what they wanted with this information and how it would be used.

Unsure at first

For the first couple of meetings Maggie was unsure whether this way of working could make a difference to her life. It was only after the second meeting that Maggie began to have thoughts about what could change for the better.

Before the plan, Maggie was using day support as the only way of having something to do or a way of going out. However, as she began to share things that she missed and that were important to her, she found that she could have a voice too as well as control over a better life.

By making a Support Plan, Maggie developed some ideas about trying some things that she had not done for a long time. This meant joining a new craft club near her own community. She also decided that, if she was ever unwell, she could receive communion from the minister at her local church. She also had some ideas about how to get closer to her own community, develop new relationships as well as have support for the existing ones.

Frustrated with being dependent on others

Although Maggie did not want many people involved, she did need help from a planner with whom she had started to feel comfortable. She chose a small group of people who would help her with her plan. It was clear that Maggie did not want close family members to assist her. One reason for this was the emotion she felt about the loss of the active life she had once led. She was frustrated at having to depend on others. Those who did support her found that they could tell just from her eyes how she was feeling.

What else was helpful about the process? In the past no one had ever told Maggie how much her support was costing, or whether what she was receiving was working or not. No one was prepared to talk about what would happen if her situation became worse.

By developing a support plan, Maggie was able to say how she wished to be supported if she were to fall or become unwell. One of the most powerful supports was a neighbour, named in the plan as her main supporter. If support services needed to know if all was well with Maggie or if she was unable to speak for herself then the neighbour and family were her trusted circle of support. The Individualised Budget enabled Maggie to ask her neighbour to give up her job and become her P.A. She could now receive daily support from a P.A. who was also a good friend.

Maggie was asked what she would tell someone considering the same change in their life:

“Anything will not do! When you are old, people think you don't matter. Just because you are a certain age doesn't mean you don't matter. Old people are ignored and at the bottom of everyone's list. If you need help, get a plan, have people listen and know who you are and make a plan for how you want your life to be! I wish I had known that the simple things I wanted could have happened. What will happen to those older people who are so unwell and tired, who can't say what they want you to do? Everyone who needs services needs a plan – and the money and help to make a difference.”

Julia's Story

This story describes life for a young woman who needed support after illness in her adult life. Julia was working as a nurse when she became unwell. The illness resulted in Julia needing care.

After becoming pregnant, Julia suffered from breathing difficulties that left her dependent on oxygen support for a lung condition. Julia felt that her life had reached rock bottom, presenting real problems not only for her but for her family too. She needed help for washing, dressing and all her personal care. Her dependence on so much support had a huge influence on how Julia managed her role as a parent and as a wife.

“So my world totally closed down into my house. I couldn’t go out and I was told I’d never work again. And I really was very, very low. My self esteem just plummeted. I felt a total burden to my husband... I had 6 different carers on different days, never knew who was coming, how long they’d stay, what they’d be prepared to do.”

Luckily, Julia’s social worker told her that she could receive an Individual Budget and have the support she so badly needed for her and for her family. This seemed too good to be true. It gave her hope for the future at last.

No longer on the scrap heap

Now that she felt she was no longer on the scrap heap, no longer isolated or trapped at home, Julia found work. She set up a coalition for disabled people and later found employment as a direct payments support services manager.

Asked about the difference between receiving an Individual Budget and a direct payment Julia said: “The first thing that happens with an Individual Budget is very different. With a Direct Payment you have something called a Community Care Assessment, where they assess whether you can eat, sleep, go to the toilet. It’s all very medical and very functional. With an Individual Budget, they throw all that out, and the first thing they do is fill out a simple questionnaire, which then determines how much money in a year you’re being allocated. And that might just be from Social Services, or it could be from other funding streams...”

Once Julia knew how much her allocation would be, she was encouraged to do a support plan. This was a refreshing experience for her. She was amazed that that no one had ever asked her what was important in her life before. She could rebuild her family life and stay out of hospital. She could now think about the things that would make a difference, like having friends.

At the end of the process, Julia also realised that she would like her husband to be her carer. With an individualised budget, she felt sufficiently in control to be able to use resources to pay for things that helped her stay well. For example, she had previously been told that her house could not be adapted for a wheelchair. Now, she was able to use her allocation to shop around and find a way to adapt her home.

Since she has had an Individual Budget, Julia has realised that she prefers to have someone else manage it for her.

“I’d like to employ somebody to actually manage my PA’s for me. I’m quite an assertive person but managing staff, dealing with holidays, sickness, cover, minor disputes, takes its toll on you. (I’d like) somebody else who... will be responsible for finding cover for holiday and sickness, and will deal with any minor personnel stuff... it’s going to be such a huge weight off my mind.”

Still some reservations

She has some reservations but feels they will be sorted.

“I think one of the down sides of Individual Budgets is (that) with choice and control also comes responsibility and work. And because I’m so busy working at my job, I don’t have a huge amount of spare time, so the things keep getting pushed back... But I’m due for a review next month and my Independent Living Fund money’s going to come on-line, so I am going to have to do a new support plan to take into account this extra funding, which will be really good because it will make me sit down and evaluate what’s worked, what hasn’t worked - and what I want to change this time

round, to make it even better than it is now.”

Julia sees her individualised support plan as an evolving document that is helping her work towards a life that matters to her. There are hopes and exciting times ahead.

George's story

In this story, we hear from a man who was the first person to receive an individualised budget from his local authority.

George has spent his life suffering from enduring mental illness.

He grew up in the countryside with his three brothers. After leaving school and becoming self-employed, he developed a psychotic condition. The Local Authority where George lives decided to introduce an alternative approach to providing resource allocation. George was invited by the co-ordinator to participate in the pilot.

Thinking about how to spend the allocation was helpful in itself

“I was allocated the amount of money that I was going to receive and was told how much it was. So I decided to spend the money accordingly, but I was trying to see what I needed in the short term - and what I needed long term. I've recently been divorced and would now like to meet somebody else, possibly to get married again at a later date.” One of the most helpful aspects of planning for an Individualised Budget was for George to spend some time thinking about what he would do with the allocation.

The Individualised Budget was also an incentive for George to come off benefits and become employed, leading to a better lifestyle with new opportunities, relationships and experiences. Over past years, while he was on benefits, George had started to drift. With his own budget came a chance to make life positive.

Getting a lot for the money

He was very clear about what he would use his allocation for. The amount was relatively small, approximately £2,000 per year. However, it was effective in meeting his requirements.

“It's tailored for individual needs. With the small amount of money that I've received, I've tried to use it as best as I can and hopefully for the money, I can do a lot with it, a lot more than perhaps you might've done if you were buying into normal social services.”

Once the allocation was agreed, the whole amount was paid into a bank account. This came as a surprise to George. A system had been set up for him to show receipts for what the allocation had been spent on. He opted to manage this himself even though there would have been support available.

The difference to his life since he received his allocation has been very positive. Several months later, George has achieved a great deal. He has taken a holiday and is now more active in his artistic work.

“Painting helps me relax and helps takes some time away - some time out... It's a way of chilling out in some ways. If I've got problems or feeling stressed out, it's quite nice to be able to paint, just to take some time away... it's quite beneficial because I see the result in the end... it's quite rewarding for me”.

Gill, the Individualised Budgets co-ordinator said:

“I think George was incredibly thoughtful in the way he went about the process. He took time to work it out (and) to think about how he would spend his money. I think he also thought very carefully about planning, not just for now but for his future as well, and how he wanted his future to be, so that all the things in his support plan were aimed at making his life work better.

In the process of coming up with their support plan, people do start thinking about how their whole life is going to work. So they start thinking about the possibilities. And I think in George's case, he was thinking in terms of actually having a holiday, having his respite...somewhere different. And during that process, he discovered that he could actually get a cheap flight to Greece, where he's got a mate. So, while he was actually writing his support plan, he went off to Greece....

Freeing

I think there's something that is actually so freeing about enabling people to think differently about... their whole life, rather than just this bit that's called Social Care or Supporting People, or Access to Work. It actually all joins up and makes somebody's life work better"