Putting
Everyone
First

Putting People First set out the Government's commitment to independent living for all adults. It called for the transformation of adult social services to enable people to shape and control their own services. The Putting People First document sets out a number of measures to achieve this, including the introduction of Personal Budgets.

A number of organisations who work with people who often have very specialised needs came together to discuss the implementation of Personal/Individual Budgets. We share the Government's commitment to a system which allows people to shape and control their own lives. However, we have a number of concerns about the way in which this is currently being put into practice, and have put together a practical guide for local authorities to ensure that they consider a range factors that need to be taken into account to ensure that Personal Budgets meet everyone's needs.

Guide Dogs

mencap
The voice of learning disability

The National Autistic Society

RNIB
supporting blind and partially sighted people

RNID
Changing the world for deaf and hard of hearing people

sense
for deafblind people

The guide is separated into seven sections as follows:

A) Is a RAS needed?

B) The role of a RAS

C) Ensuring equity in the process

D) Questionnaire design

E) Piloting questionnaires

F) Funding allocations and specialist support services

G) Self-Assessment Questionnaires and Support Planning

A. Is a RAS needed?

The allocation of appropriate funds to a Personal or Individual Budget is critical to its success. There is little point in people being given control of an inadequate budget – this does not give a person the power to shape services to meet their needs. In many ways the use of a standardised questionnaire does not represent a personalised approach. It is worth authorities being aware that there are potential pitfalls with the Resource Allocation System (RAS) process and that there are other approaches.

Some authorities have taken an "outcomes focussed" approach, which takes people's aspirations for their lives as its starting point. The evaluation of the Individual Budget pilots concluded that there was no consensus about the benefits of RAS questionnaires and called for a debate about the relative merits of RAS, outcomes focussed approaches and the system currently used for direct payments allocations. In the absence of a national debate, we believe that the first issue authorities should consider is whether developing a RAS self-assessment questionnaire is the approach they want to take.

B. What is the role of a RAS?

A standard questionnaire is unlikely to be able to take account of the needs of everyone in a personalised way. Attempts to do this result in very long and complex RAS questionnaires. The RAS, if used, should give an indicative amount early in the process. However, after full assessment and support planning, this amount is likely to have to be adjusted to take account of some of the issues set out below. The simpler the RAS, the more often adjustments are likely to be needed.

C. Ensuring equity in the process

The way in which questions are asked, either in a self-assessment questionnaire or verbally during assessment and support planning, can inadvertently create difficulties for certain individuals. The checklist below sets out some of these issues, although it is not intended as an exhaustive list.

A personalised approach to assessment and support planning should be better able to meet the needs of everyone. However, our organisations are aware of some key issues that may mean the system fails to deliver for some individuals.

1. Communication support needs

People may require communication support for a range of reasons. They may need an advocate or support from their family or carers to help facilitate meaningful communication if they have an autism spectrum disorder, dementia, a mental health problem or a learning disability, an interpreter if they have a sensory impairment or equipment if they have a disability affecting speech. Communication needs can relate to communication with others, understanding others' communication or both.

■ **Will your assessment and support planning process adequately address communication support needs?**

2. Mobility

Questions on mobility need to look beyond whether someone can physically move around their home or travel outside the home. For example, those with an autism spectrum disorder or a learning disability may have no physical impairments, but need support to plan and undertake a journey. Someone with an anxiety-related mental health problem or obsessive-compulsive disorder may need a supporter to reduce anxiety or to minimise routines that have an impact on the time it takes to leave the house. Someone with sight loss may get around a familiar environment with minimal difficulty, but busy streets or unfamiliar routes may be impossible. A person with profound hearing loss may find it difficult to use public transport because they cannot hear announcements. A frail older person may know how to plan the journey but be concerned about places to rest on the route.

■ **Does the process include both mobility around the home and travel outside the home, including transport?**

■ **Do questions assume that the only people who have difficulty with mobility are those with a physical disability? Or are other needs taken account of, such as visual impairment, memory problems, learning disability, mental health problems or autism spectrum disorder, including, for example, support to read timetables, identify the right bus or get to the bus stop safely?**

3. Personal safety

There should be consideration of personal safety outside the home. For example, some people may lack a sense of danger or be socially naïve and allow strangers to take advantage of them.

■ **Is the personal safety of those who may need support in the community taken into account?**

4. Access to information

Information is vital to daily living. People may need support with access to information because they need different formats such as large print Braille, audio, British Sign Language or easy read documents, or because they need support to understand that information, or communication support.

■ **Is access to information taken into account?**

5. Prompting

A number of people accessing social services require support to carry out daily living tasks, such as getting up and dressed, making themselves a meal and doing housework. The support required may not only be physical in nature.

People with an autism spectrum disorder, a learning disability or who have mental health problems may be physically able to dress themselves or cook themselves dinner, but may need instructions or prompting to do so.

Does the process take account of the needs of people who, whilst physically capable of carrying out tasks, require prompting to do so?

6. Variable needs

The process needs to work for people who sometimes, perhaps only occasionally, need support.

People with fluctuating conditions find it hard to know if they should answer the questions according to the experiences they have on "good days" or "bad days".

For people with visual impairment, the degree of difficulty they face may well fluctuate depending on lighting conditions, either because of lighting in different locations, dark winter evenings or glare from low sun at some times of year.

Some people have emergency support needs. For example, people with high functioning autism or Asperger Syndrome may be able to lead relatively independent lives, but would need support if something happens that is seemingly minor (such as a light bulb blowing) but very distressing to the individual. People with mental health problems may require support in a crisis but may not otherwise demonstrate a need for support.

■ **Are emergency support needs included in the process?**

■ **Is it made clear to those with fluctuating conditions or whose needs vary how they should approach the process?**

D. Questionnaire design

7. Questionnaire wording

When developing a self-assessment questionnaire, local authorities should ensure that it is clear what is being asked in every case.

It should be recognised that imagining what their life might be like without support will be a difficult concept for some people, particularly those with an autism spectrum disorder. It should therefore be ensured that parents and carers are able to support people to fill out the self-assessment survey. Advocates should also be made available to those who need them.

Questions in the format: "All the time, once or twice a day, once or twice a week, occasionally, never" can cause difficulties if not worded well. Do you need help with shopping all the time, or only once or twice a week because you only shop once or twice a week?

■ **Are all the questions clear and unambiguous?**

E. Piloting questionnaires

8. Pilots

Piloting self assessment questionnaires with disabled and older people before they are put into use is the most effective way to identify inadvertent problems. It is essential to pilot with as wide a range of people as possible as different people will have different issues with wording.

Has the questionnaire been piloted by people with:

- Physical disabilities?
- Learning disability of different levels?
- Mental health problems or lack of capacity due to dementia, or other similar condition?
- Sensory loss including visual impairment, hearing impairment and dual sensory loss?
- Those who have used support services for some time and those with new needs?
- Autism spectrum disorders?
- Fluctuating conditions including mental health problems?
- People whose first language is not English (including those who use sign language)?
- People from key minority communities in your area?
- People living in rural and urban parts of your area (if relevant)?

F. Funding allocation and the cost of specialist services

9. Specialist services

Some people's needs will inevitably be more expensive to meet than others', for example because they have unusually complex needs, or need support from more than one person.

For some people, support will be provided by a PA, who needs some basic skills, but usually not specific training or a professional qualification. For others, professional support is required, which comes at a higher cost. This might be people with profound and multiple disability, an autism spectrum disorder or sensory impairments requiring specialist language skills.

Local authorities have a duty to provide services which meet the assessed needs of an individual. The amount of money allocated to a Personal Budget must be sufficient to meet eligible needs, even if this is significantly greater than the indicative amount calculated by the RAS. There must be no maximum allocation.

■ **Does the system take account of the different costs of specialist services. And those with very high and complex needs?**

■ **Is it implied that there is a maximum possible budget? Is it made clear that the RAS gives on indicative amount or does the paperwork imply that this is fixed?**

■ **How are funds allocated to people who only need to access them in an emergency?**

10. Brokerage

Is brokerage free at the point of access available in your area or are people expected to purchase it with their budget allocation? If the latter then the Personal Budget must include an allocation of funds for brokerage for those who need it. If not, these people will have less support available to them to live independently.

G. Self-assessment questionnaires and support planning

Local authorities need to be clear about the process for completing questionnaires and what support people may need. Self-assessment works well for those who have been in receipt of support for many years and have a clear idea of their personal aspirations and support needs. Others may need support, which may include advocacy, support from family or social worker, accessible information and communication support. Local authorities have a duty to assess those in need of support, including those who would not be eligible for council funded services. The process must include an assessment by a professional for those who want one.

People may under-assess their needs. People with recent acquired disability may either be in denial about the level of difficulty they face or may "accept their fate" and so they settle for a higher level of dependency. They may also not be aware of support that would help, especially if they need technical equipment not in general use. Those with complex needs may not have the self-awareness required to understand the support they require.

If a person already has a good support package in place, they may currently be able to carry out the task. For example, a person with the right support in place may not display challenging behaviour, but if that support were removed this would change. Self-assessment and support planning need to allow people to think about what their life would be like if they didn't have their current level of support.

People may take questions too literally and therefore misrepresent their support needs. For example, a person may feel they can cook a meal for themselves, when they can only heat a meal in the microwave with supervision. A person may be able to get dressed in the morning, but if this takes two hours and causes pain and exhaustion then they may need support.

■ **How does the process ensure that those who underestimate their needs are supported to get the resource allocation they need?**

■ **Does the introduction to the questionnaire, and the way the assessment is carried out, make it clear how the person is to approach completing it e.g. assuming they didn't have the support they have currently?**

Summary checklist

Do you want to develop a RAS self-assessment questionnaire? Consider the alternatives before making this decision.

If you do decide to develop a RAS questionnaire, are your staff clear about the role of the RAS in the process of assessment and support planning?

Ask the following questions:

- [ ] **Will your assessment and support planning process adequately address communication support needs?**

- [ ] **Does the process include both mobility around the home and travel outside the home, including transport?**

- [ ] **Do questions assume that the only people who have difficulty with mobility are those with a physical disability? Or are other needs taken account of, such as visual impairment, memory problems, learning disability, mental health problems or autism spectrum disorder, including, for example, support to read timetables, identify the right bus or get to the bus stop safely?**

- [ ] **Is the personal safety of those who may need support in the community taken into account?**

- [ ] **Is access to information taken into account?**

- [ ] **Does the process take account of the needs of people who, whilst physically capable of carrying out tasks, require prompting to do so?**

- [ ] **Are emergency support needs included in the process?**

- [ ] **Is it made clear to those with fluctuating conditions or whose needs vary how they should approach the process?**

- [ ] **Are all the questions clear and unambiguous?**

☐ **Has the questionnaire been piloted by people with:**

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- People living in rural and urban parts of your area (if relevant)?

☐ **Does the system take account of the different costs of specialist services. And those with very high and complex needs?**

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For more information

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