Supplementary Submission to Productivity Commission
—Disability Care and Support--

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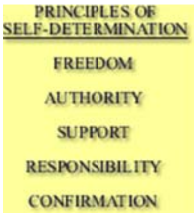
SACID would like to take this opportunity to congratulate and thank the Commision for a very thorough and comprehensive document which demonstrates a great depth of understanding about the issues which people with disabiity and where appropriate their families, have to deal with. It was refreshing to be left with the impression that we have been not only heard but also listened to.

Below are a few points for further consideration.

"Rigorous" assessments and the notion of Self Determination



PRINCIPLES OF SELF-DETERMINATION

FREEDOM

AUTHORITY

SUPPORT

RESPONSIBILITY

CONFIRMATION

The Principles of Self Determination are

Freedom… to live a meaningful life in the community
Authority… over dollars needed for support
Support… to organize resources in ways that are life enhancing and meaningful
Responsibility… for the wise use of public dollars
Confirmation… of the important leadership that self-advocates must hold in a newly designed system.

Information about the Centre can be found at *http://www.centerforself-determination.com/*
Also see, **attach #1—***The Meaning of Self-Determined Lives in Publicly Funded Systems of Long Term Care and* **attach #2**—. *Communicating Self-Determination: Freedom, Authority, Support and Responsibility by Tom Nerney of the Centre for Self Determination*

We would also urge you to read Simon Duffy's writings, "Unlocking the Imagination" and "Keys to Citizenship". They and many others can be sourced via the "writings" tab on Simon's website. http://www.simonduffy.info/Simon_Duffy_Website/Home.html

Resource allocation system (RAS)

It is essential that consideration be given to the provision of a form of self- assessment such as the Resource Allocation System, which applies in the UK. All evidence finds that most people DO NOT over assess and in fact tend to make savings. Any resource allocation process must be arrived at from a place of trust in and of the honesty of the individual being assessed.

Commissioner Scott asked me to find out how self-assessment was working in the UK and other places. I contacted John Waters, a man whom I have had ongoing email contact with, whenever I have had questions about inControl and how it works in the UK. John is head of Research and Evaluation, at in Control Partnerships. Should it be thought useful to talk to John, his contact number is Mob: 07403413476. In the box below is the answer which I received from inControl's John Waters.

In reality the (self) assessment takes place as a discussion between the person their family and the social worker. who reach an agreed position on the assessment, the allocation is then an indicative allocation until such time as an appropriately costed support plan has been agreed. If anything the process builds in financial checks and balances rather than removing them.

The point of the self-assessment is that the framework is simple-easy and understandable, creating a 'deal' between the individual and the state..

It's a mindset thing… if the attitude is that disabled people are after screwing the state then, you'll create a dynamic where people feel, "I'll try and screw the state". If you create a 'fair deal', that is respectfully administered, well, people respond responsibly, on the whole and those who don't you just have sensible checks in place.. If the commissioner wants to build a system based on an assumption that people are dishonest and will try and grab everything they can , there is little any one will say to dissuade them that view.. I fear. The challenge you've been set Is unfair, the assumption of corruption is floored, the assumption should be of honesty, in effect you are being asked to prove a negative..

All I can say is its genuinely not the case here, vast majority of people take the responsibility of the self-assessment very seriously and using the money too ...

We have 250,000 people all with a personal budget and a government set on a course to reduce public deficit at an unprecedented pace and to an unprecedented degree who have just reaffirmed an intention to make personal budget available to the other 1.25 million eligible people over next 2 years.

The system has clear and rational guidelines to ensure allocations of funding are fair and transparent. It is based on points awarded to answers to a self-assessment questionnaire (SAQ) which aims to identify an individual's support needs.

It is highly offensive and not in the spirit of self-determination, when assumptions are made that people with disability and where appropriate their families, are “rorting” the system or accused of being “squeaky wheel’s” just because they are stating what their true needs are. Very rarely does it occur that people seeking supports and services funding, overstate their need.

More to the point they make very real attempts to make savings and not to ask for more help than they need. Mostly they are very aware of the fact that the more they get the less someone else gets and they don’t like being judged as greedy and “lucky” just because they have spoken up about their needs. Despite what others may think and make ill-informed judgements about, over allocations do not occur.

The Resource Allocation System calculates how much money an individual is likely to need for their social care and support needs. Each question in the self-assessment form has a number of points attached to it. Each self-assessor is then able add up the points and the total number of points coincides with an amount of money. See **Attach #3&4,** this is an ‘indicative amount’ – it gives a figure comparable with cost of that level of support to use to develop a support plan. Easy Read factsheets: 1-12. — In Control and Me—http://www.mencap.org.uk/page.asp?id=15063 can be sourced from the mencap website. Also **Attach#5** is “Self-Assessment Pilot Project” from “Enhancing the Efficiency and Effectiveness of the Assessment in Community Care” completed by the Personal Social Services Research Unit of the Manchester University

In New Zealand the Disability Support Services, (DSS), Group at the Ministry of Health has developed a new model for disability support services. See **Attach #6** and the link below. Investigating a New Model for Supporting Disabled People - Key Projects – Disability
http://www.moh.govt.nz/moh.nsf/indexmh/disability-keyprojects-model

Attach #7 is the “Report on Self-Assessment Models Practice and Tools” which is not able to be accessed from the website. It was compiled by the NZ Ministry of Health for the Needs Assessment Service Co-ordination Association of NZ… It consists of 3 parts.
a) Literature and document review of international self-assessment best practice
b) Stocktake and analysis of self-assessment practice in NZ
c) Recommendations on the design and implementation of self-assessment in a NZ context

All in all it seems that while models of self-assessment could be widely used, it may not necessarily be for everyone. In our enthusiasm for the personalisation of disability supports and services, those of us influencing policy must not remove the ability of individuals to have the opportunity to decide if this is what they want to do.

Self-assessment should be available for those who choose, and not as the only pathway to receive disability supports and services funding. Some disability supports and service funding recipients may need different sorts of assistance and tools made available so as to enable them to take part in a self-assessment process and they may be unable or not wish to do a self-assessment.

Same Opportunities for All

SACID advocates for and support the Shutin Campaign, information about which can be found on www.shutin.org.au We invite you to read the position paper prepared by People with Disabilities…**Position Paper - *Accommodating Human Rights***

This PWD position paper provides a detailed analysis of the rights contained in the UN Convention on the Rights of Persons with Disabilities (CRPD) in relation to housing, and housing and support for people with disability.

Within this document there is a chapter called Challenging Segregation as Choice, we commend the whole document to you and in particular this chapter. Our comments can be found in **Attach #8. Challenging Segregation as CHOICE**

It is essential that people who are currently living in institutions, group homes, supported residential facilities under block funding arrangement, to have access to a direct payment of an individual funding package over which they would be supported, if that is what they want, once they understand what it may mean for them, to self-manage using their current allocation? **I.E., WHAT IT COSTS IN THEIR CURRENT SERVICE.**

In the US there is a movement to close down institutions using a Government Initiative called **Money Follows the Person.**

MFP grants are made available to support people with disability who require long term care to move away from institutionalised support arrangement and into living and support arrangements which reflect their wishes to…

(1) Live in the most integrated community setting of their choice;
(2) Exercise meaningful choice and control over their living environment, services, and service providers; and
(3) Obtain high-quality services in a manner consistent with their preferences.

Enacted by the Deficit Reduction Act of 2005, the Money Follows the Person (MFP) Rebalancing Demonstration https://www.cms.gov/DeficitReductionAct/20_MFP.asp is part of a comprehensive, coordinated strategy to assist States, in collaboration with stakeholders, to make widespread changes to their long-term care support systems.

"With the history and strength of the Real Choice Systems Change (RCSC) grants as a foundation, this initiative will assist States in their efforts to reduce their reliance on institutional care, while developing community-based long-term care opportunities, enabling the elderly and people with disabilities to fully participate in their communities".

More information can be found at https://www.cms.gov/CommunityServices/30_RCSC.asp

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Many people of all ages, with disabilities or chronic illnesses, strongly prefer home and community-based services (HCBS) to institutional care. However, although spending for home and community-based services has increased dramatically over the past decade, institutional services still dominate Medicaid funding for long-term care in many States. Creating a more balanced service delivery system is a major goal for CMS and States.

In 2007, CMS awarded $1,435,709,479 in MFP grants with States proposing to transition over 34,000 individuals out of institutional settings over the five-year demonstration period. 30 States and the District of Columbia were awarded grants.

***Using Person Centered Planning Grant's** people with disabilities or long-term illnesses are supported to reside in their homes and participate fully in their communities. The overarching agenda was dual purposed:*

The purpose of the FY'07 PCP Implementation Grants was to support States and territories in enabling individuals with disabilities or long-term illnesses to reside in their homes and participate fully in their communities. The overarching agenda was dual purposed:
(1) to change the basic model of care planning from one that is directed by the needs of institutions and provider agencies to one that responds to the needs of the individual and
(2) to assist states and territories in developing ways to identify the strengths, capacities, preferences, needs and desired health and quality of life outcomes of the person who needs assistance.

PCP Implementation Grants were primarily focused on these core elements:

SACID believes that it is essential for all people with disability, and more particularly those with intellectual disability, because it is they, apart from those who are NOT aged or in prison, who make up the highest number of people living in institutions to be supported to live like most other Australians.

Some family/parent advocates continue to insist on using the mantra of "choice" when they really mean that 'they" think it is quite acceptable for a member of their family who has a level of disability which requires extensive and specialized assistance, to live in institutional or congregate styles of living.

They refer to the "flocking" of Australians who do not have disability, to congregate living arrangements, (ie, multi storied, apartment/ retirement village style of living), as an example of "modern" thinking about where the general population "chooses" to live. This style of housing is often "chosen" by young un/first married/retirees as a first or last of life option. The current high cost of purchasing a family home also has an effect on how and where this group of Australians live.

That these particular groups usually do not have serious disabilities and that they can make choices about how they spend their day away from their home and how they make connections with their outside community, is not considered, nor is it acknowledged in these assertions,

It is SACID's contention that an individual with a disability might also, with adequate and appropriate levels of individualised support, select to reside in such an arrangement and this would not be considered an "institution". It WOULD however be one if the complex houses ONLY people with disability or has an uneven bias of having residents with disability.

According to ABS 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2009, In the Australian aged community, less than 8% of that population "choose" to live in such congregate accommodation and on average, the length of time they live in such arrangements is around 6-8 years and then they die!

Many seniors, who when living in hostels and nursing homes, while understanding the inevitable-ness of their situation, continue to lament the fact that they are not living in their own home, in their own street, in their own community.

Usually having a disability is an "all of life" experience and in the 21st century, there is overwhelming evidence available to support the fact that it should never be anyone's expectation that it is "good enough" for this particular cohort of Australian citizens to live in what is considered by the previously mentioned groups to be a "time of life" accommodation decision.

They have the option of moving out or moving on. To date many persons with disability who have a requirement for long term living and support assistance often DO NOT.

Protection from Abuse, Neglect and Exploitation.

If it is essential for people with disability (usually those with intellectual and particularly those with profound severe and multiple disabilities, who more often than not CANNOT speak for themselves), to have **LEGISLATED PROTECTIONS** to ensure their safety, rights and general living standards are monitored, inspected, issues identified and the outcomes of those inspections are publicly reported and the monitoring agency reports directly to Parliament.

The establishment of an independent model of monitoring, inspection, accountability, reporting and investigation must occur from a nation-wide perspective.

Programmes such as the Victorian Community Visitors Scheme and an Office of the Senior Practioner with the Senior Practitioner are examples of how direct disability service providers must be monitored in relation to the use of unscrupulous and/or restrictive practices as they are applied to a small number of people who may be either a danger to themselves or to others.

Currently there is no legislated requirement in Australia for the Mandatory Reporting of such practices similar to that which is available to children and the aged. A Senate Enquiry in 2007 http://www.aph.gov.au/hansard/senate/commttee/committee_transcript.asp?MODE=YEAR&ID=80&YEAR=2007 resulted in amendments to the Aged Care Amendment (Residential Care) Bill 2007.
These amendments are. **Attach#9**

1.3 The purpose of the Bill is to amend the Aged Care Act 1997 to provide new measures to protect aged care residents, including:

- *a regime for compulsory reporting of physical and sexual assaults of people in aged care;*
- *protections for approved providers and staff who report assaults of people in aged care;*
- *establishment of complaints investigation arrangements through new Investigation Principles; and*
- *establishment of the Aged Care Commissioner to replace the existing Commissioner of Complaints.*

As a matter of urgency the requirement for the Mandatory Reporting of such practises must also be legislated to ensure the protection of vulnerable adults, between 18 and 64 years of age, many of whom are people with an intellectual disability, who are unable to speak up for themselves, who have no family and no advocates to do it on their behalf.

See UNCPRD **Article 16 Freedom from exploitation, violence and abuse**
5. States Parties shall put in place effective legislation and policies, including women- and child focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Why identify people with intellectual disability as requiring "specific mention". I have attached #8 a copy of the easy English version of Valuing People from the UK. The full strategy document can be found at http://www.valuingpeoplenow.dh.gov.uk/valuing-people-now#non SACID's contention is, that if the UK felt it important enough to devote an enormous amount of time and effort into working specifically around the needs of people with intellectual disability then so should Australia. It should not be a "bone of contention" in discussion with other disability groups. Historically more due to ignorance and misinformation, there has always been a divide between those other groups AND IT HAS ALSO ALWAYS BEEN EXCUSE USED BY SUCCESSIVE GOVERNMENTS TO ABDICATE FROM THEIR RESPONSIBILITY REGARDING ANY COHESIVENESS AROUND HOW DISABILITY SERVICES ARE MANAGED.

What has often happened in the past when these discussions have occurred is that governments will say that if the various disability groups can't be united in what they want from any new arrangements why should it bother to make any changes. AND NOTHING GETS DONE!!!!

IT IS GOVERNMENTS' RESPONSIBILITY TO LISTEN TO ALL STAKEHOLDERS AND SOMETIMES TO TAKE A HARD LINE BY ACKNOWLEDGING THAT THERE A SOME DISABILITY GROUPS WHICH REQUIRE DIFFERENT SORTS OF SUPPORT ARRANGEMENTS AND MAKE EFFORT TO ENSURE THAT NO GROUP IS DISADVANTAGED BECAUSE IT SEEMS THAT ALL GROUPS DON'T COME TO AN UNDERSTANDING OF EACH OTHERS NEEDS.

This is a prime example of just how individual the requirements of people with disability are and how we all must acknowledge and accept the difference and continue to work on making appropriate and ground breaking changes for the benefit of all.

Co-payments

It must be remembered that may people with disability and their family carers, whose ONLY income is a Centrelink income support payment are already seriously economically disadvantaged and usually have no opportunity to amass assets, liquid or otherwise, and live from fortnight to fortnight on inadequate payments. In light of the predicated future increases to energy and water costs, which for some are absolutely essential to maintain health and wellbeing, the requirement for co-payments would just add further impost to those who are already struggling to make ends meet.

This is another unfortunate and perhaps unintentional idiosyncrasy which is the result of imposing the ability/capacity of those who are aged, many of whom have had opportunities over their whole lives of amassing assets/income and having such things and superannuation/savings from which extracting a co-payment is perfectly acceptable. This is another incidence where policy makers must have a serious understanding "all of life" V "time of life" circumstances.

Family Carers.

It is essential for the current propensity to exploit family carers as a cheap labour force, to cease.

There must be capacity in any assessment process to ask the family carer what it is the want EXACTLY. i.e.,

- Do they want to provide care and support to their family member?
    1. No…
        - Family carer relinquishes and make alternative arrangements in consultation with that family carer
    2. Yes

- How long do they envisage being the principle carer?
    - As long as they humanly able? (Many of us don't trust paid workers),
- What do they need to continue in their caring role? This might be in the form of a
    - combined disability and aged care community
    - home support package
    - family carer package
    - Side by side accommodation in which either person could continue to be supported upon the death or incapacity of one or the other.
    - Shared care arrangement.

- For when we are no longer able to physically provide care it is essential to have a planned and well supported "Moving On" arrangement before we fall to bits completely. This is to ensure that as much as possible:
    - Unnecessary distress is avoided for all parties, caused by sudden uprooting from familiar place and care.
    - The person we are caring for has the chance to gradually assimilate into any new accommodation arrangement, rather than being thrown in at the deep end on the death or serious incapacity of a parent/carer.
        - It has occurred in SA and other states I am sure, that upon the sudden death of the sole family carer, with whom an adult with intellectual disability has lives for upward of maybe 60 years, that they have been placed, (with little support), in Supported Residential Facilities (SRF's—read hostel) and left to the vagaries of whomever lives in it and whomever runs it not to mention whatever society throws at them. This is often something with which they have never had to contend and they can become incredibly "lost" and at great risk of harm, because of their vulnerability.

Supporting family carers in a tangible way by such things as a break away for a couple of weeks a year, payment for work performed in the care and support of their family member, purchase of goods and services< such as washing machines/dryers/microwaves/accessible transport etc., to assist with the support of the family member, payment into a private health fund, etc., could make the difference between a carers ability to continue in their supportive role and of relinquishing the care of their daughter or son in an untimely and unplanned way, having the potential to cause unnecessary and sometime permanent psychological damage to the person being relinquished.

Adequate resources must be made available to the person with disability to cover the additional costs of disability which are unusual in a non-disability household and which will enable their supported participation in their community and relieve the carer of the responsibility of full time care thus encouraging their own participation in away from home activities, a much healthier option for all.

How Payments are made.

By A Legislated requirement for a Direct Payment (see UK Direct Payments Act info at http://www.legislation.gov.uk/ukpga/1996/30/contents), into a dedicated bank account which is linked to an accountability facility. Such decisions about how, when, where and with whom it is spent, comes AFTER THIS**. Attach# 9… Building upon Direct Payments as Key of the Wider System of Self-Directed Support** as an example of how Direct Payments of Individual budgets have been implemented in the UK.

While it states in this document, first month payment is made up front and then monthly, we believe that in order to support flexibility, and cover emergencies it is important that a first payment of at least 3 months in advance is made and perhaps quarterly payments would reduce administration and associated costs from both the individual and the agency's part. After all if we are working from a point of trust this just make sense.

Any "slippage" money remaining at the end of any financial year must remain with the individual and be allowed to "roll over' for at least the following 2 years, (3 years in all), to enable planning for the purchase of big ticket items, such as washing machines, air con, refrigerators, microwaves, even accessible transport. All of which can be seen as a disability related and appropriate purchase, due to the paucity of income support payments the replacement of such items are often unaffordable thus leaving the person with disability in circumstances less favourable to their good health and well-being,

All recipients of disability supports and services funding must be allowed use their allocation to choose whomever they wish, to provide them with support. Utilising support from local community and friendship networks encourages connection with local community and can have the effect of strengthening such relations AND most importantly provides for the safety and security of the person because of what would be a caring relationship with someone who is well known to them and with whom they trust and feel most comfortable.

Advocacy

It is essential for any NDIS to have a component in it for the independent support of self-advocacy.

For people with intellectual disability and where appropriate their families, to successfully participate in the self-management or self-direction of their supports and services, they MUST have tools available to them so that they can learn about self-managing their supports and services, not to mention about their rights and responsibilities.

They must be well and appropriately supported to make their own decisions to be able to live their life in a way which "makes most sense to them".

This support must be separate from any provision of services and must support the sovereignty of the person at all times.

People with intellectual disability in particular have need of specialised support to learn about their rights and responsibilities and it must be provided in a safe and supportive environment.

Their families also have similar needs. The often overwhelming responsibility of caring for and supporting a daughter or son with intellectual disability and or profound severe and multiple disabilities, doesn't leave much space for learning about and understanding just what and how to self-manage means as well as what "Having Rights", means. The current void in advocacy funding has seen the erosion what used to be a very well informed and active self-advocacy movement.

THE MEANING OF SELF-DETERMINED LIVES IN PUBLICLY FUNDED SYSTEMS OF LONG TERM CARE

- Thomas Nerney Center for Self-Determination August, 2007

This first written description of "Self-Determination" was based on a set of *principles* and in a demonstration of their efficacy, funded by a grant from the Robert Wood Johnson Foundation, targeted a group of individuals with significant brain injury and a group with developmental disabilities beginning in 1993. The principles have remained as a foundation for this effort ever since:

Freedom
The ability to make life decisions about where and with whom one lives and what important things one undertakes that parallels in every important way the decisions that those without disabilities make everyday.

Authority
The ability to control a targeted amount of public dollars together with private money in order to craft a life plan that results in the everyday freedoms that all Americans desire and the expectations that the lives of those with disabilities will mirror, with appropriate assistance when necessary, the lives of others in this society.

Support
The organization of these resources in ways that are unique for the individual and address the support needed because of a disability with a more holistic way of planning and budgeting that address perennial issues often lost in the system of traditional long term care: a place to call home, sustained relationships, community membership and for adults the production of private income through the world of business and commerce.

Responsibility
The commitment for the wise use of public dollars and with added flexibility in public funding seeking a more cost effective way to support individuals with disabilities. From its very inception Self-Determination challenged the high cost of "serving" individuals with significant disabilities with very few discernable outcomes that would be acceptable to a person without a disability.

The movement toward self-determined lives for individuals with disabilities has its roots in the civil rights movement as well as the patient autonomy movement and has been expressly articulated by people with disabilities ranging from those with psychiatric labels to those with intellectual disability labels. Organizations have developed that carry the ideals of accessibility—both physical and social, freedom from coercion and freedom to pursue everyday lives infused with high expectations. The first written expression of an organized approach to rethinking the federal Medicaid program began with a publication funded through the Robert Wood Johnson Foundation National Program Office on Self-Determination at the Institute on Disability, University of New Hampshire. (Nerney and Shumway, 1996).
Over the last twelve years this approach has evolved into specific recommendations for changes in public policy, Medicaid funding mechanisms, individual allocations and

personal budgets, eliminating forced impoverishment and a deeper view of what constitutes quality assurance.

Public Policy

Self-Determination challenges the view that public funding is only about providing assistance based on a person's deficits. Taking into account the particular assistance an individual may require, Self-Determination posits a set of expectations that veer fundamentally away from a constricted view of medical necessity and toward creating policy that promotes meaningful lives. In its bare essence it promotes the view that public assistance is a vehicle to enable individuals who experience disability to live a life of everyday freedoms together with an acceptance of the responsibility to contribute to this society and to one's own welfare.

Medicaid Funding Mechanisms

Many states and the federal government now recognize two of the structural reforms necessary for system change of this magnitude: independent and conflict of interest-free assistance to individuals and fiscal management agencies to disburse the public dollars on behalf of an individual with a mandate to both account for the dollars spent and address both benefit and federal/state tax and labor issues. Various self direction initiatives have reinforced these changes. Self-Determination goes further by questioning many contemporary service definitions and rate setting that limit creativity in planning and budgeting while failing to address issues of relationships, community and poverty.

Personal Budgets

Individual allocations, ideally set below current traditional expenditures (for those in high cost settings) are then translated into unique budgets with the following set of expectations:

- *Individuals would have a safe place to live where they control who enters their home.*
- *Individuals establish real community membership.*
- *Individuals sustain current and facilitate new long term committed relationships.*
- *Individuals engage in the production of income through work and/or self employment as well as participate in other income and asset development initiatives including individual development accounts.*

New Quality Assurance

The quality assurance paradigm would then move from *satisfaction* with services (the commercial consumer standard for product satisfaction) to quality outcomes associated with the four domains listed under personal budgets. This approach has the added benefit of better addressing health and safety issues by insuring that long term relationships are instrumental in advocating for the individual with regard to that person's health and safety.

COMMUNICATING SELF-DETERMINATION: FREEDOM, AUTHORITY, SUPPORT AND RESPONSIBILITY

Thomas Nerney

The Tools of Self-Determination

With the vast extension of self-determination projects across the country and the wide adoption of the principles of self-determination, it may be helpful to step back for a moment and reflect on what we have learned thus far about some of the technical and structural issues associated with truly successful individual budgets, support brokering and fiscal intermediaries. Not every issue is yet crystal clear and it is anticipated that some ambiguity may remain especially in those projects that are still experimenting with systems change.

These three areas do not exhaust the range of system change issues but at this stage appear to be fundamentally necessary for the success of self-determination at the personal and family level. Typical human service systems find it difficult to make these fundamental changes. Other changes in personal planning and the restructuring of provider agencies also need to be addressed.

Addressing conflicts of interest in the present human service system has always presented itself as critical to the implementation of self-determination. If individuals with disabilities are ever going to attain a degree of freedom then those freely chosen to assist them will also need to be free. This simply means that no one gets to assist an individual/family unless that person is invited and remains totally committed to the individual with a disability and not to existing "services" or organizations. Those who assume these new roles will have to embrace the principle associated with rejecting overt or unconscious conflicts of interest. This is sometimes a long, arduous process.

One of the not so surprising results thus far reveals that creativity in planning appears to be very much related to avoiding conflicts of interest. Assisting individuals to achieve meaningful life goals (the goal of self-determination) appears to require both freedom and creativity. The same appears to hold true for cost effectiveness. Simply "buying back" existing services, with the option to move to another provider, doesn't meet the ultimate goal of self-determination nor is it cost effective. In fact, the federal Medicaid statute currently guarantees provider choice. That said, however, many individuals and families have little experience outside typical human services nor do they necessarily trust the current system to support them in meaningful ways outside typical human services. Developing trust between individuals with disabilities/families and human service system representatives, and gaining experience from those who pioneer self-determination, are important aspects of this change.

EMERGING BEST PRACTICE IN SELF-DETERMINATION

Two relatively innovative assumptions are beginning to under gird the self-determination movement for all individuals with disabilities. One is that all persons will "have their own place", and, two, that virtually all individuals can work in meaningful employment and/or produce income through the development of microenterprises. Folks with disabilities may indeed want to live with another person but that is always a freely chosen situation and one susceptible to re-negotiation when necessary. More and more projects across the country are gradually changing the goal from "getting a job" to one of "producing income". This enables everyone to understand that there are many ways to secure employment and to start a small business. Individuals within their budgets can (with assistance from a variety of sources) contract directly with employers for co-worker support, transportation and even training. Individual budgets can be used to help secure or pay down the cost of equipment necessary for a small business.

IDEAL STANDARDS FOR INDIVIDUAL BUDGETS, SUPPORT BROKERING AND FISCAL INTERMEDIARIES

INDIVIDUAL BUDGETS

Based on current best practice individual budgets meet ideal requirements for self-determination when the budget is actually controlled by the person and their freely chosen allies. Public dollars are now seen as an ongoing investment in the person's life and the obligation to be responsible as well as contribute to one's community becomes part of the budget development. In many demonstrations these ideal standards are only partially reached, but this represents an important step in the right direction. This means that the following is in place:

Individually created

The person with a disability and freely chosen family and friends create individual budgets. This includes the creation of unique line items that reflect the distinct dreams and ambitions of the person with a disability.

Authority over Personnel

Any person who works for the individual with a disability is hired and can be fired as well. In fact all employees and consultants work for the person and that person's social support network. Even if another organization assumes some legal responsibility to become the employer of record, all personnel and consultants work for the person with a disability.

Flexible

Within approved amounts, dollars can be reasonably moved from line item to line item as long as the essential supports are maintained. New line items may also be created as well as old ones erased.

INDEPENDENT SUPPORT COORDINATION

The linchpin to the success of creative, highly individual budgets and life plans is the function that is variously referred to as independent support coordination, personal agents, or independent brokering. What is important with regard to this function is the potential for conflict of interest. This is a person who may help with plan development, assist in organizing the unique resources that a person needs and even assist with ongoing evaluation of these supports. There are many ways that this function can be carried out from family members doing it to case managers assuming new roles. One creative project allows the person with a disability to select anyone they know and trust and pays them separately if necessary. Sometimes ongoing and regular support coordination is also required and some individuals are actually including this in their individual budget since it meets the test of a "service". The characteristics of an independent brokering function include:

Independence from Service Provision

It is important to keep this function separate from any form of service provision in order to avoid both the appearance and the reality of conflict of interest. Even those "brokers" who have great integrity should not be put in a position of divided loyalties. Current systems which feature service provision and support coordination may take years to accomplish the transition. Many individuals with disabilities and families have relationships and loyalties in place that need to be respected while this transition proceeds.

Real Authority

Whether the person is an independent contractor, or an independent agency is used, this function has to carry some state, county or publicly sanctioned authority if this person is going to adequately represent the person with a disability. Again, it should be clear that the person who carries out this function works for the person with a disability. It is always their choice who provides this function.

FISCAL INTERMEDIARIES

Fiscal intermediaries are simply organizations, places really, where an individual budget gets parked or banked. The functions carried out by a fiscal intermediary include, but are not limited to, check writing for all bills and personnel costs, tax withholding, paying worker's compensation, health insurance and other taxes and benefits that might be appropriate depending on the individual's budget. The fiscal intermediary works for the individual and remains accountable for insuring compliance with all federal and state laws. Minimum standards include:

Individual Budget Isolation

This means that every person's individual budget is isolated from any other and certainly from traditional provider contracts. The money is available upon receipt of an approved budget and is accounted for by the fiscal intermediary to the public funding authority as well as to the person with a disability.

Conflict of Interest Free

Fiscal intermediaries have no other duties that conflict with their role. This means that they are independent of service provision. If the fiscal intermediary is a government or quasi government agency, it has specific rules that prohibit the use of this money for any other purpose.

Close to the Person and the Community

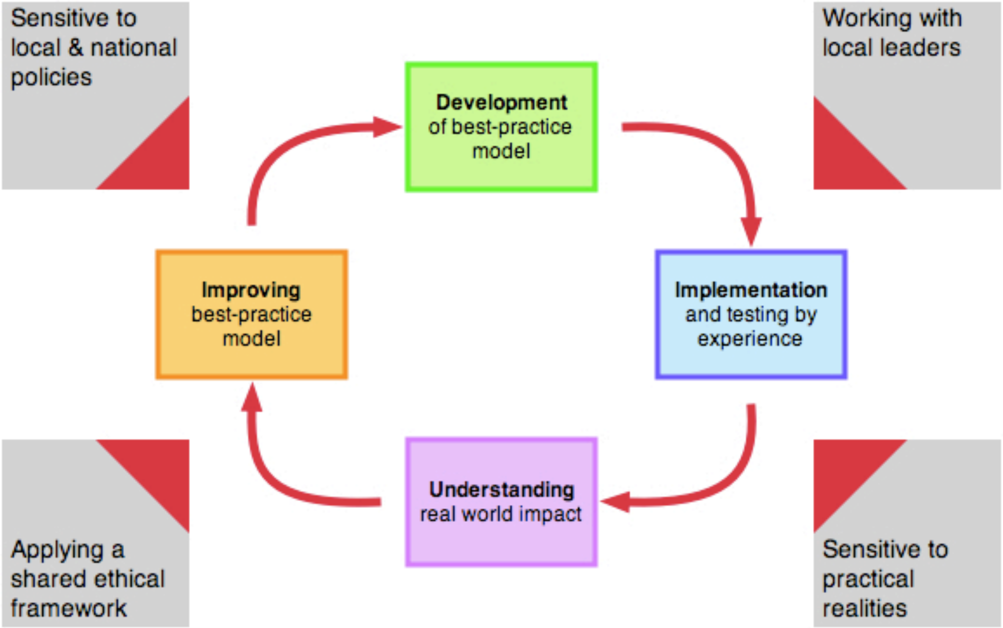
Fiscal intermediaries, to the extent possible, should be generic, neighborhood, community organizations that enable the person with a disability to create relationships with personnel who work there in regular community settings. The closer this function moves to a "neighborhood bank" the better for the person with a disability.

These are ideal standards. Some human service systems can move faster to implement them. Others may take much longer. They deserve more discussion, examination and further demonstration. There are numerous ways to meet these ideal standards long term. Further demonstration and even experimentation will bring new knowledge and insight into improved ways to implement these ideal tools of self-determination.

Appendix - What is a Resource Allocation System?

in Control has been developing its approach to Resource Allocation since its foundation in 2003. During that time we have worked with local and national partners to improve our model and the latest version of our Resource Allocation System is Version 5. Almost all local authorities currently offering people Personal Budgets are using one of in Control's Resource Allocation Systems which can be downloaded, used and adapted by our members from the in Control website: www.in-control.org.uk

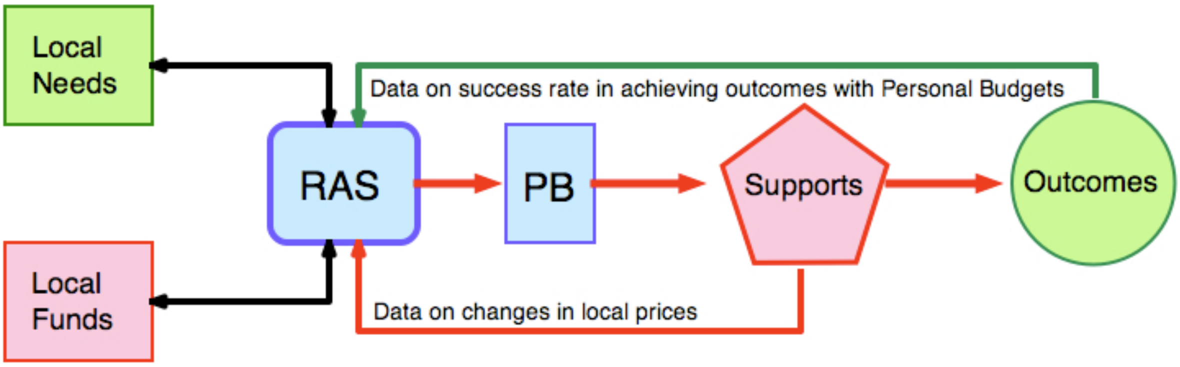
in Control's approach to innovation and development is set out in the diagram below. It has proved a very successful systemic approach - linked to in Control's role as social innovation network.



Building on earlier work in Scotland in Control began working on systems to allocate resources in 2003. Version 2 was published in 2004, Version 3 was published in 2005, Version 4 was published in 2006 and Version 5 was published in 2007. These models were developed, like all of in Control's materials as part of this process of co-production with our members.

How RAS works

Any RAS should allocate appropriate levels of resources to individuals who require support according to their needs and circumstances. The RAS should also define the outcomes that these resources must be used to achieve. Systems can be configured locally to draw information from both the needs of the local population and local costs. The system can be calibrated so that it is tuned to local priorities and can be adjusted over time to reflect changing conditions.



Criteria for a successful RAS

A resources can be allocated by any number of rules to any number of purposes; but in Control and its members are only interested in creating a Resource Allocation System that is ethical and effective. Together with our members we have identified 12 properties of a successful RAS. They are set out in the table below:

Criteria	In order that system...
1. Control	...gives the person needing support or those closest to them genuine control of the money allocated
2. Transparency	...makes it easy for those administering the system and those using a personal budget to make decisions
3. Efficiency	...runs smoothly, is easy to use and requires the minimum resources possible to administer
4. Innovation	...encourages people to use resources flexibly and find the best possible means of meeting their needs
5. Collaboration	...encourages those administering the system and those needing support to work together productively
6. Equity	...treats all individuals fairly, respecting relevant individual needs and circumstances.
7. Integrated	...operates as an integral part of a wider system of Self-Directed Support
8. Realism	...reflects the local economic situation, local prices and changes over time
9. Contribution	...avoids creating poverty traps and encourages people to earn, save and build social capital
10. Portability	...lets people who need support move home without undue cost, complication or uncertainty
11. Prevention	...allocates resources at the right time and minimises the risk of people coming into crisis.
12. Citizenship	...recognises and define needs in the terms of rights and entitlements.

RAS Version 5 - ‘State of the Art’

in Control’s RAS Version 5 is the current state of the art in Resource Allocation Systems. It provides Personal Budgets that are very sensitive to need and yet it is practical and efficient. Its basic methodology is described below.

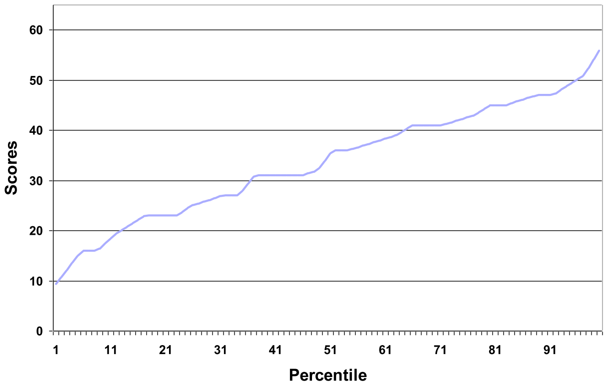
RAS Version 5 uses a simple scored self-assessment questionnaire (SAQ), which is then linked to a set of locally-defined funding levels, allowing people who need support and the local authority to quickly and easily determine both the amount of money any individual needing support can reasonably expect in their Personal Budget, and what outcomes their support plan must address.

The SAQ measures the impact of a person’s disability on their life in a number of key areas. Each area is scored and the total is adjusted according to the amount of support reasonably available to each person from their friends and family. In this way people with similar levels of needs in similar circumstances can be allocated the same level of funding. Each level of funding is based on local intelligence about how much money has been needed for people in similar circumstances to meet their agreed outcomes. This emphasis on agreed outcomes with strong links to local costs and experiences of planning ensures the system is robust and is seen to be fair and equitable.

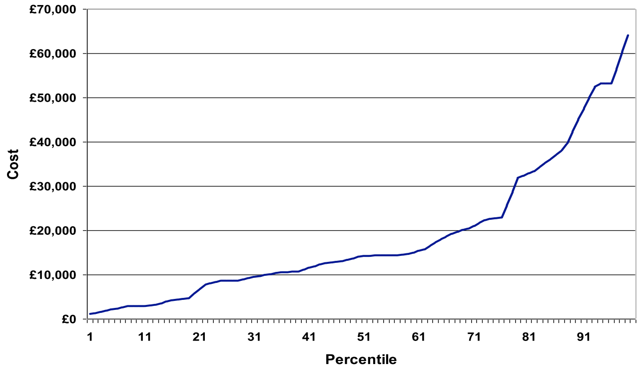
Needs Scores					
8	23	27	36	41	46
12	23	31	36	41	47
16	23	31	37	42	47
16	25	31	38	43	49
19	26	31	39	45	51
21	27	32	41	45	56

Using an assessment that provides a scored level of needs and building up local intelligence about local costs RAS Version 5 provides a dynamic framework that can allocate appropriate levels of resources attuned to changing market conditions.

RAS Version 5 analyses the needs levels of the local population of peopling needing support using the scored needs assessment, and identifies the scores of each percentile of the population. The costs of support for each individual are analysed in the same way. Initially cost information is drawn from existing care packages however once the system has been operational for some time it is possible to re-calibrate the allocation levels using information from people who have control of personal budgets. In this way some of the inequities of traditional funding can be removed.

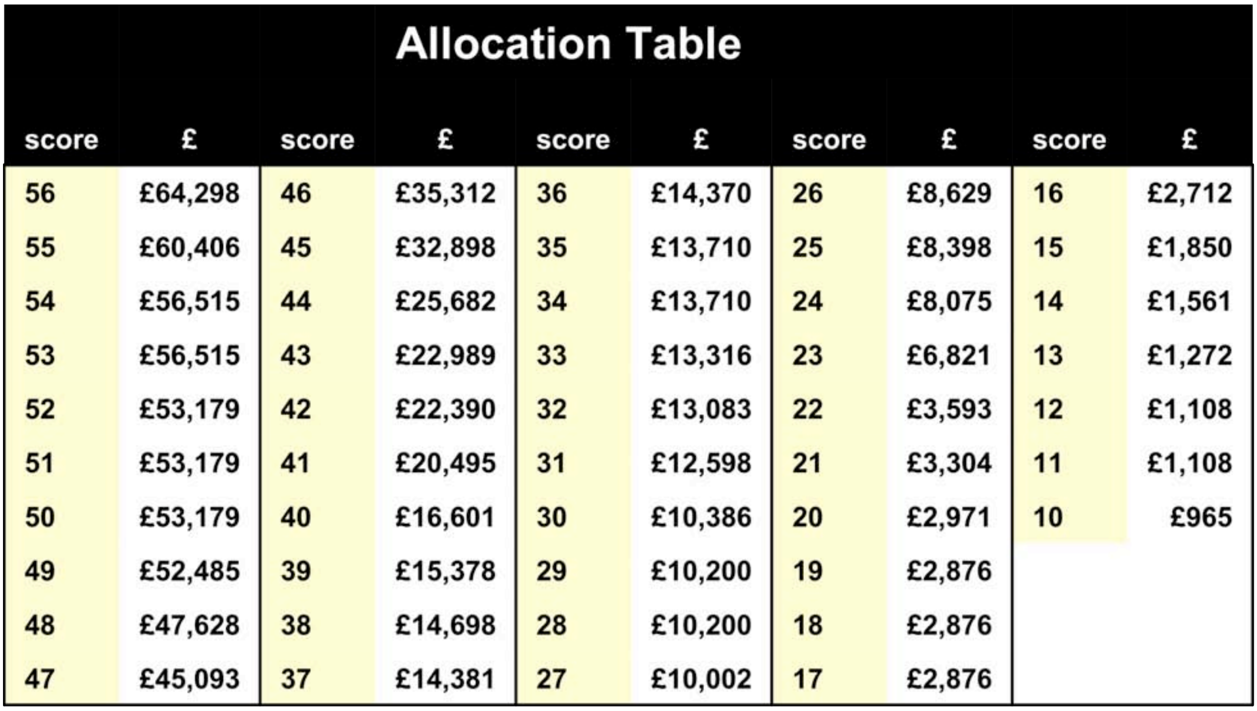


An allocation table is then produced by connecting the scores from each percentile in the population with the costs at that percentile. In the following example a sample population of 36 people illustrates the methodology.



Analysing the above data it can be seen that 10% of the group score at most 18 points and that 10 % of the group are allocated at most £2,876 so 18 points is afforded £2,876. Similarly 50% of the group score at most 34 points and that 50% of the group are allocated at least £13,710. So 34 points is afforded £13,710. Following this method the following allocation levels can be set.

This methodology provides a way of setting local funding levels that are demonstrably fair and rational. Allocations produced by the system are seen as indicative of a reasonable sum until an appropriate plan has been agreed with the local authority. Presently indications are that up to 20% of allocations are felt to need some adjustment, this adjustment ensures individuals are treated fairly and also ensures the system is dynamic and can change over time. As actual allocations and needs scores can be used to re-calibrate the system periodically.



Allocation Table

score	£	score	£	score	£	score	£	score	£
56	£64,298	46	£35,312	36	£14,370	26	£8,629	16	£2,712
55	£60,406	45	£32,898	35	£13,710	25	£8,398	15	£1,850
54	£56,515	44	£25,682	34	£13,710	24	£8,075	14	£1,561
53	£56,515	43	£22,989	33	£13,316	23	£6,821	13	£1,272
52	£53,179	42	£22,390	32	£13,083	22	£3,593	12	£1,108
51	£53,179	41	£20,495	31	£12,598	21	£3,304	11	£1,108
50	£53,179	40	£16,601	30	£10,386	20	£2,971	10	£965
49	£52,485	39	£15,378	29	£10,200	19	£2,876		
48	£47,628	38	£14,698	28	£10,200	18	£2,876		
47	£45,093	37	£14,381	27	£10,002	17	£2,876		

Resource Allocation System
for Self-Directed Support

Introduction

This is a short discussion paper. It is based on initial work done in Wigan as part of the In Control Programme. The working assumption of the In Control Programme is that it is better for people to have a realistic idea of what resources they might have to plan with.

The purpose of our first seminar was to see if the group could identify a reasonable process to achieve this goal. There is more detailed analysis underlying this discussion paper, but at this stage it seems important to quickly share the initial outcomes of that work in order that we can identify any likely problems in taking these ideas further.

Key principles

We assumed the following key principles in designing a Resource Allocation System (RAS):

- We should aim for the lowest feasible transaction costs (the costs involved in actually allocating funding – i.e. much of the existing care management process)
- We must work within Fair Access to Care
- We must develop a system that is workable for Wigan (but which can be suitably adapted for other authorities)
- We must use definitions of need that are clear

Fair Access to Care

It was agreed that Fair Access to Care and its criteria of need should only determine eligibility for services and should *not* dictate the specific allocation of funding. This decision is in line with FAC guidance and is reinforced by the fact that the risk criteria set out in FAC, while they are useful in determining someone's priority for social care, don't serve as useful proxy for level of support required. (That is, you can have a critical need that could be met very cheaply, while a have lower level of need that would be more costly to meet.)

For the purposes of our first discussion FAC was left to one side with the assumption that for those people who were genuinely cut out by FAC would only be able to access preventative or other services (e.g. services for families). Once this work has been developed further we will have discussions with the Department of Health to remove any ambiguity about the relationship between our RAS and FAC.

Funding Levels

The group analysed the existing allocation of services in Wigan to individuals to see how resources were presently allocated. We found that resources were already allocated in ways that were densely clustered around certain levels. (More detailed information will be set out in a separate spreadsheet.)

Level	**Expend. (pa)**
7 (Red)	150,000 plus
6 (Orange)	75,000
5 (Yellow)	50,000
4 (Green)	30,000
3 (Blue)	15,000
2 (Indigo)	5,000
1 (Violet)	500

The group reviewed this information and made the following decisions:

- The top level of funding (red) should not have any specific figure attached to it, this funding level should in a sense be deemed ‘too much’ and the greatest possible scrutiny should be given to services at the red level.
- The bottom level of funding should not attract a particular funding level; instead this level should be associated with helping people access community services and flexible low level sources of funding (e.g. Wigan’s Carers Grant Scheme).
- Overall the other funding levels should remain as they are.

Therefore the actual banding should be as follows:

Level	**Expend. (pa)**
7 (Red)	No fixed allocation
6 (Orange)	75,000
5 (Yellow)	50,000
4 (Green)	30,000
3 (Blue)	15,000
2 (Indigo)	5,000
1 (Violet)	Low cost flexible funds

Criteria for making an allocation

The group then began to work backwards to determine whether suitable criteria could be applied to justify the different levels of funding. Overall three different kinds of criteria were identified and within each criteria there are different options. Clearly there are significant questions as to whether this could really work and whether the criteria would stand up to real practice, however the group certainly felt that, at first blush, something like the following criteria might work.

Support Needed: level of support required to achieve independence[1]	High	Needs someone to be around then 24 hours a day.
	Medium	Needs support to achieve many ordinary tasks each day.
	Low	Needs only some support with key tasks.
Community Support:	Minimal	Person is socially isolated, has lost contact with family and friends.
	Normal	Person may live relatively independently, but still has the backing of friends, family and the wider community.
	Intensive	Person lives with others (e.g. family) and their life is integrally bound up with the lives of others.
Complexity	Complex	Person has support needs that are relatively unusual or which cause increased levels of risk and which are therefore going to need higher levels of funding.
	N/A	The above criteria do not apply.

This is very much a first stab at analysing the factors involved in making a funding decision and the interrelationship between these criteria and other funding streams (esp. ILF, SP and DLA) needs to be investigated further. However it did seem to those involved that it was exactly these kinds of factors that were presently determining Resource Allocation decisions.

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[1] It is even possible that the tests for DLA could be used as a proxy for level of independence or at least as an indicator (i.e. in the first instance those tests would apply, subject to other factors).

The Application of the Criteria

The following chart sets out how those criteria could be applied to justify the Resource Allocation decisions:

Need	Community Support	Complexity	Level
High	Minimal	Yes	6
High	Minimal	No	5
High	Normal	Yes	5
High	Normal	No	5
High	Intensive	Yes	4
High	Intensive	No	3
Medium	Minimal	Yes	4
Medium	Minimal	No	3
Medium	Normal	Yes	3
Medium	Normal	No	3
Medium	Intensive	Yes	3
Medium	Intensive	No	3
Low	Minimal	Yes	2
Low	Minimal	No	1
Low	Normal	Yes	2
Low	Normal	No	1
Low	Intensive	Yes	1
Low	Intensive	No	1

Clearly this approach ends up squeezing down the 18 different possible permutations down to only 6 different bands. So there is an inevitable crudeness to it. However as the banding mirrors the existing allocation it is possible to argue that for all its inevitable simplifications it could put people in a position to show how they could make better use of the existing levels of resource.

This approach also *does* discount family support. However, unlike the present system which in theory (if not in practice) is prepared to discount family support at 100% this approach sets out an explicit partnership between families and the community at large. In effect family support is discounted at an increasingly lower level as the level or disability and complexity of support increases.

The table above is the first attempt to factor the criteria into the proposed bandings. This table will be amended after those involved have been able to comment on this approach in more detail.

This approach will be subject to further discussion within Wigan. In addition other authorities, (e.g. Bradford) are exploring whether this approach has anything to offer them. From Bradford has also come a further redefinition of ‘support need’ in to 4 different levels:

1) Can manage for 24 hours without help

2) Can be safely left for 2 hours without help

3) Needs 24 hour supervision

4) Needs 24 hr support & night time attention

In addition it has been proposed that it may be useful to have 3 levels of complexity. Both these options will be tested further.

Other issues

In addition to this fundamental allocation issue there are a number of further issues to resolve amongst which are the following:

Accountability	Like all systems there will need to be a system to enable people to challenge the allocations. However there can be incentives built in to avoid unnecessary levels of dispute (e.g. agreed allocations can be allowed to go through more quickly, disputed allocations may need more scrutiny)
Scrutiny	It is proposed that the level of scrutiny is made proportionate with the level of funding. This seems an excellent and appropriate way of further developing the system. For example the existing panel system could be adapted to focus only on the red band or on disputed allocations. The level of detailed planning required could also increase with the bands as could the level of monitoring.
Community services	This whole approach assumes that services for people in the violet level are still critical to all people with disabilities and that funding needs to be allocated to these services (e.g. a supported employment service). However the low levels of individual funding at these levels might be too expensive to administer. Therefore at this stage the idea is to focus individual funding at the higher levels and to focus on other forms of community funding. However it would be ideal to build in a community chest or ‘Local Area Coordination’ approach that supports Person Centred Planning and flexible low-level funding.
Gross funding	Throughout we have assumed gross funding levels. Although there are different options, at this stage, we are presuming that the authority would commit to the gross level of funding and would work with the individual to bring in any additional income (e.g. ILF). If people are able to achieve higher levels of funding than the gross funding levels there should be a share of the benefits between the individual and the authority.
Service brokerage	Ideally funding for many people for service brokerage will be built into the individual funding allocation. However at the lower levels of funding service brokerage may need to be delivered through community services. Further analysis of the possible costs will be set out in the follow-up paper to this discussion paper.
Insurance	Any system will need to deal with problems where

things go wrong. Although it is possible for the local authority to take responsibility for this there are two further approaches (a) encourage individuals to ‘save’ to cover their own risks or (b) to put funding aside in some kind of insurance fund. This will be pursued in the developed proposals.

Interim funding

It will also be important to allow for short-term funding. In fact short-term funding that is not ‘guaranteed’ can encourage people to work in a positive way to bring expenditure back under budget.

Reassessment and self-assessment

At the moment the assumption is that the local authority will reassess needs on a frequent basis. However on the proposed model there may be disadvantages to too frequent reassessments, encouraging a certain defensiveness in planning and service design. Instead it may be better to focus on longer-term reassessments or just encourage self-assessments and reassessments triggered by the individual.

Convertibility

This system will only lead to significant advantages if the funding is ‘convertible’ into new and different forms of service. Hence we must also look at ensuring the right rules are in place to restrict how resources can be spent.

Vouchers

There may also be room to incorporate vouchers into this process where there are choices to be made about the provider.

Levels as maximums

It is important that these levels are not treated as crude caps on costs as this would be inconsistent with existing guidance. However there is no problem on insisting on a certain cap if there is evidence that an appropriate service can be funded at that level.

There may also be room to encourage people not to plan ‘up to’ the level (although this may not work). In other words we could encourage people to treat the level as a likely maximum and celebrate support arrangements that come in below the maximum. However this should not slip into the micro-management of people’s own planning.

MINISTRY OF HEALTH
MANATŪ HAUORA

Disability Support Services

Introducing the New Model for supporting disabled people

15 March 2011

Who we are

Jenny Moor – Development Manager. Disability Support Services, Ministry of Health (Programme Leader)

Anne O'Connell – Group Manager. Disability Support Services, Ministry of Health (Programme Sponsor)

and other Ministry staff involved in aspects of the work

Ruth Gerzon & Lawrence Chok – Inclusion Aotearoa

Why do we need a new way?

Disabled people want

a good life and

more choice and control over support they receive

MINISTRY OF HEALTH

MANATŪ HAUORA

Disability Support Services

In 2006 MPs set up a Select Committee to talk to disabled people, families and service providers

Ministry of Health meetings with consumers highlight need for – flexibility, support for families, workforce and access to information – DSS strategic plan and work programme formed from this

The Committee’s report is given to Parliament

Ministry of Health research good practices here and overseas, including Local Area Coordination

New Model for supporting disabled people developed

What is different about the new model?

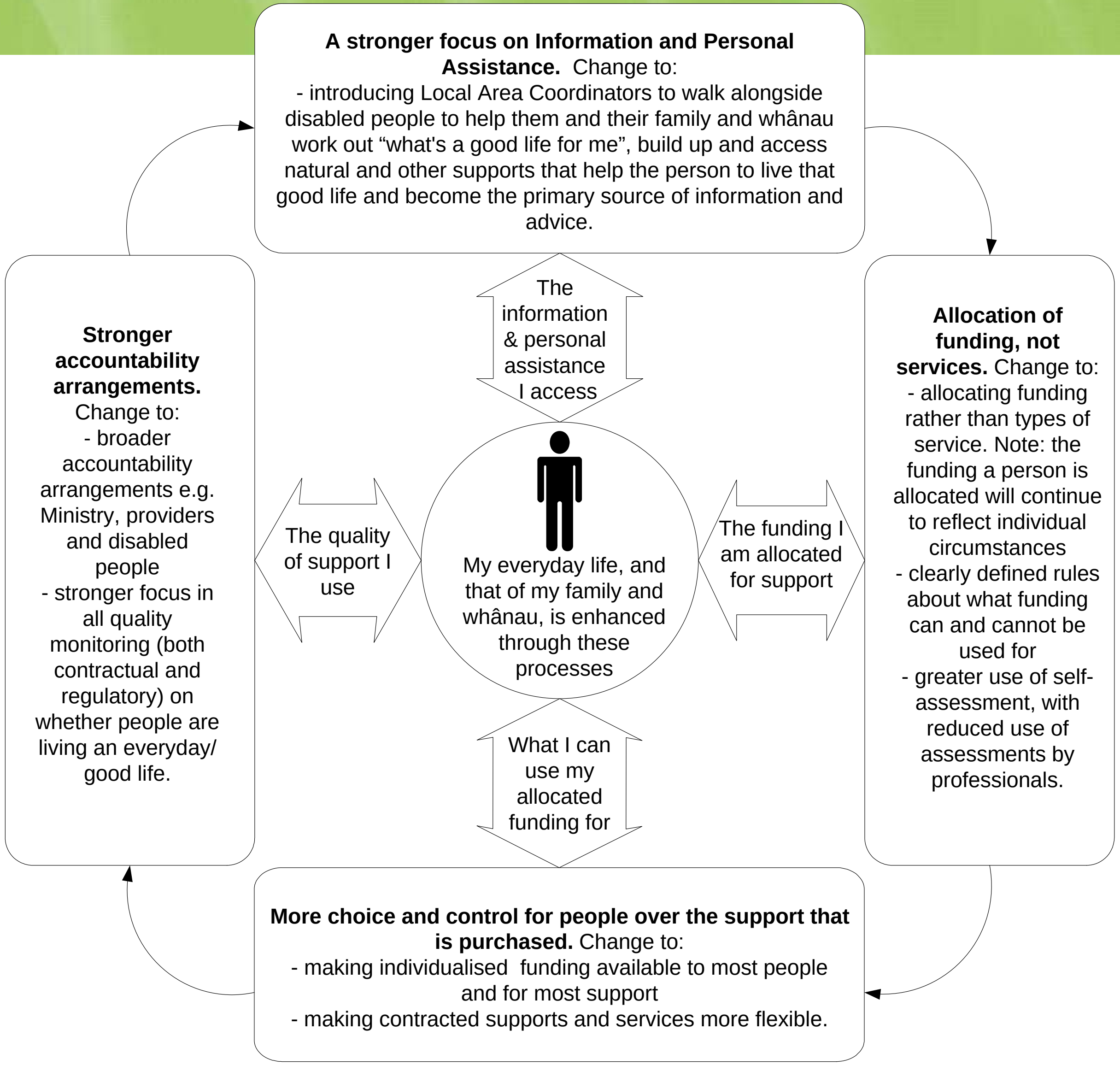
OLD WAY	NEW WAY
Someone else makes decisions about what support you get and when you get it	With support, you decide what's important to you to have a good life

MINISTRY OF HEALTH
MANATŪ HAUORA

Disability Support Services

The New Model

This is the model Cabinet approved



A stronger focus on Information and Personal Assistance. Change to:
- introducing Local Area Coordinators to walk alongside disabled people to help them and their family and whânau work out “what's a good life for me”, build up and access natural and other supports that help the person to live that good life and become the primary source of information and advice.

Allocation of funding, not services. Change to:
- allocating funding rather than types of service. Note: the funding a person is allocated will continue to reflect individual circumstances
- clearly defined rules about what funding can and cannot be used for
- greater use of self-assessment, with reduced use of assessments by professionals.

More choice and control for people over the support that is purchased. Change to:
- making individualised funding available to most people and for most support
- making contracted supports and services more flexible.

Stronger accountability arrangements. Change to:
- broader accountability arrangements e.g. Ministry, providers and disabled people
- stronger focus in all quality monitoring (both contractual and regulatory) on whether people are living an everyday/ good life.

My everyday life, and that of my family and whânau, is enhanced through these processes

The information & personal assistance I access

The funding I am allocated for support

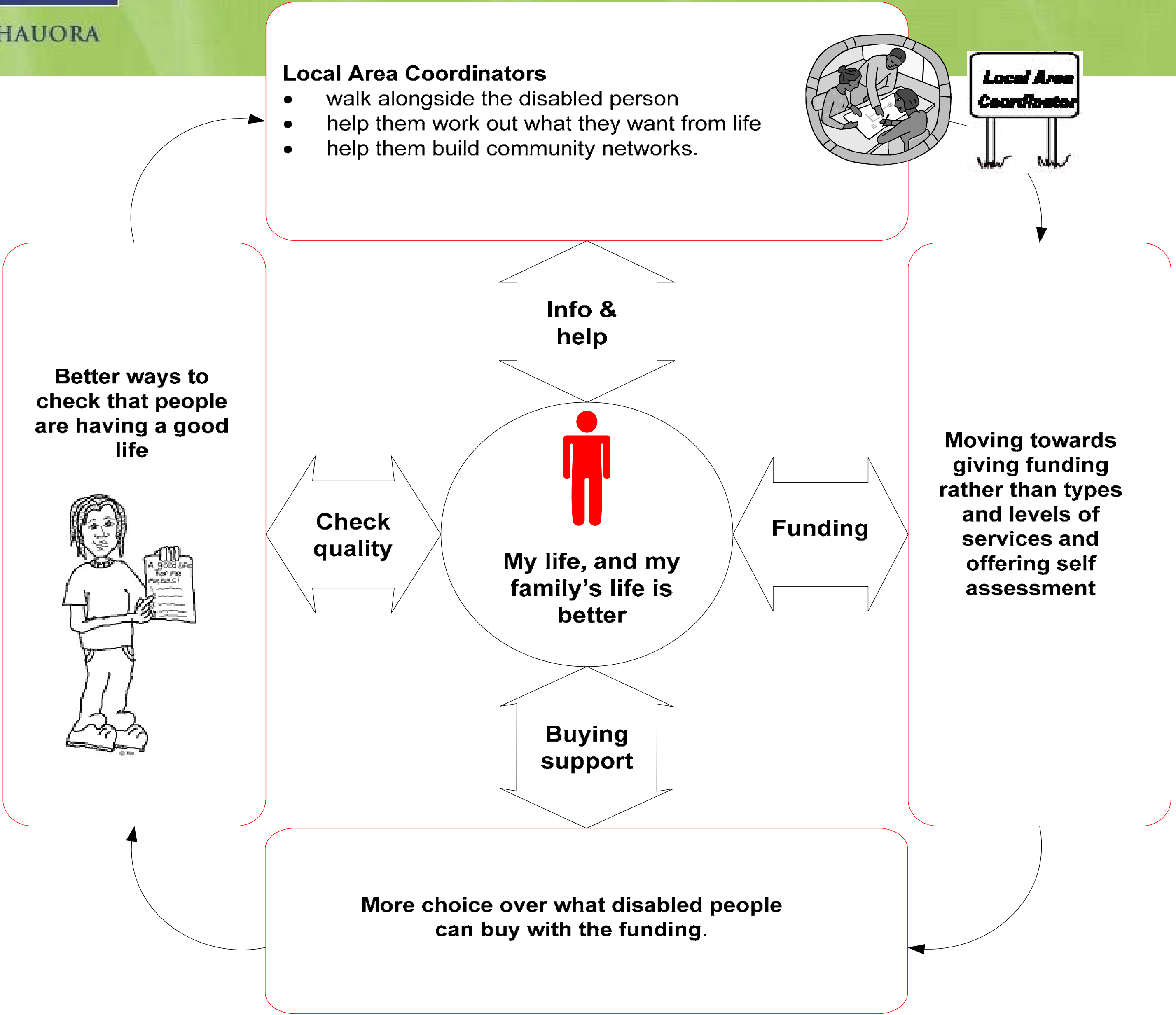
What I can use my allocated funding for

The quality of support I use

MINISTRY OF HEALTH
MANATŪ HAUORA

Disability Support Services

The New Model - another version in plain language



Local Area Coordinators

- walk alongside the disabled person
- help them work out what they want from life
- help them build community networks.

Moving towards giving funding rather than types and levels of services and offering self assessment

More choice over what disabled people can buy with the funding.

Better ways to check that people are having a good life

Info & help

Check quality

Funding

Buying support

My life, and my family's life is better

Local Area Coordination

The most visible part of the new model in the demonstration will be

Local Area Coordination

How does Local Area Coordination work?

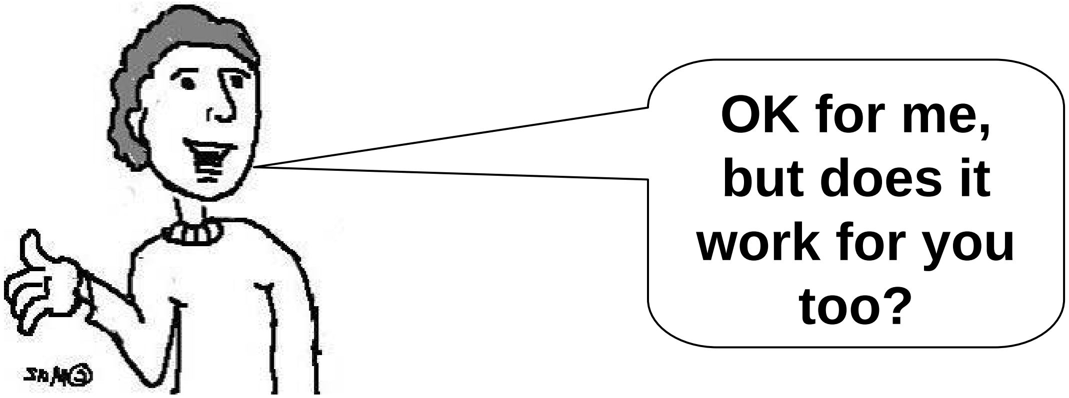
A local area coordinator (LAC) will help you :

- get information
- work out how you want to live
- build relationships with people and organisations in your community or town
- work with the community to encourage them to include disabled people

What else is the new model about?

Funding, not services – allocate dollar value rather than type of service, self assessment

What you can use the funding for – expanding IF, increasing flexibility

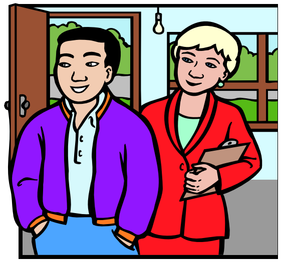


Accountability – for everyone – Ministry, providers, service users, focus on quality and having a good life

What is Individualised Funding?

Individualised Funding (IF) is a way of paying for support services

What can you do with IF?



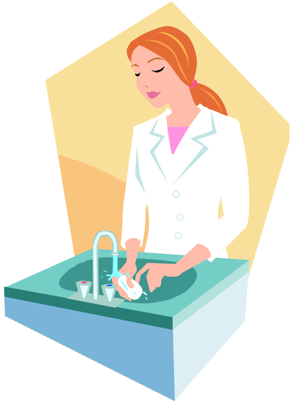
You can choose:

who comes into your home

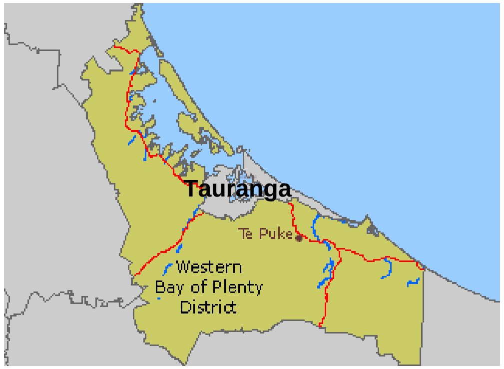
when they come

what they do

how much they get paid (provided it’s at least the minimum wage)



Demonstrating the New Model

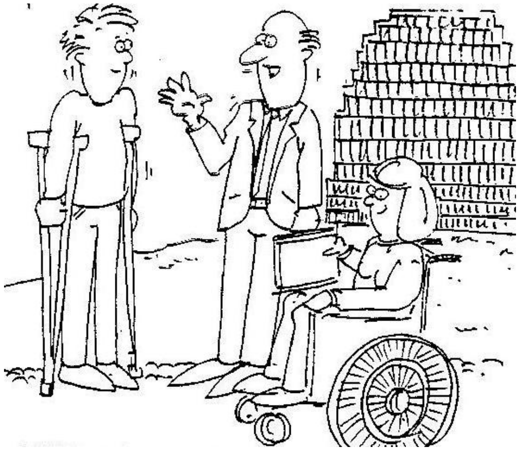


Western Bay of Plenty/Tauranga has been chosen as the first place to test out some elements of the New Model

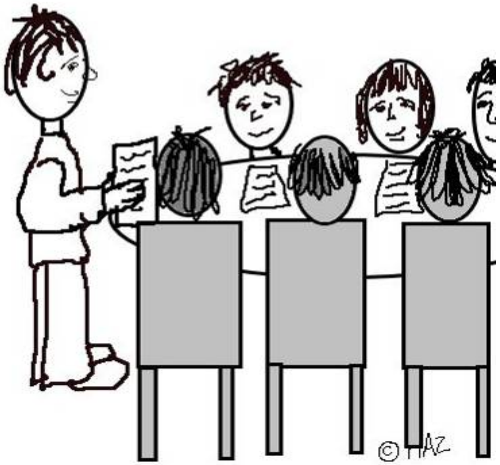
INCLUSION AOTEAROA

Inclusion Aotearoa are supporting the Ministry of Health with this Demonstration project

Community Engagement



We want to work closely with the community to share ideas, and to refine and evaluate the model



Inclusion Aotearoa has set up a local working group to work with them and the Ministry of Health to decide what will work here

A National Reference group is being set up as a strategic forum for development of the New Model and its demonstration

For further information:

Inclusion Aotearoa

Web site: http://inclusionaotearoa.co.nz

Phone: (07) 3124191

Email: inclusionaotearoa@gmail.co.nz

or write to P O Box 3017, Ohope, Whakatane

Ministry of Health Disability Support Services

New Model project page:
http://www.moh.govt.nz/moh.nsf/indexmh/disability-keyprojects-model

Self-Assessment Models, Practice and Tools within Disability Support Services

Prepared for -

Arotake Hiahia Hānga Whakarite o Aotearoa
NASCA
NEEDS ASSESSMENT SERVICE CO-ORDINATION ASSOCIATION

on behalf of the Ministry of Health -

Carol MacDonald

November 2010

Contents

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Thank you to those who contributed openly and freely to the stock-take through the interviews; we appreciate their knowledge and enthusiasm. Thanks to Lyn Rasmussen, NZ NASCA for organising the interviews.

I would also like to thank the individuals within New Zealand and internationally who have supported this work through their advice, expertise and the provision of documents for the literature review, in particular, John Waters, Christian Brand and Michael Kendrick.

Acronyms

CSCI	Commission for Social Care Inspection
DSS	Disability Support Services
FFACS	Fair Access to Care Services
IB	Individual budget
IBSEN	Individual Budgets Evaluation Network
IF	Individualised funding
LLAC	Local area coordination
NASC	Needs Assessment and Service Coordination
PSSRU	Personal Social Services Research Unit
RAS	Resource Allocation System
SAP	Single Assessment Process
SAQ	Self-assessment questionnaire
SDS	Self-directed support
SSAQ	Supported self-assessment questionnaire

Executive Summary

This report was compiled for NZNASCA on behalf of the Ministry of Health to inform the implementation of the new model/framework to support disabled people. It comprises three parts: a literature and document review of international self-assessment best-practice; a stock-take and analysis of self-assessment practice in New Zealand; and recommendations and on design and implementation of self-assessment for the New Zealand context.

Literature Review

The literature and document review included both published and unpublished material, where available. A challenging aspect of the review was that 'self-assessment' is rarely identified as a specific programme component and has seldom been explicitly studied or evaluated. References to self-assessment tend to be incidental in other published material and where self-assessment has been explicitly addressed, the discussion is largely descriptive in nature.

Because of the limitations of the available literature, much of the material used for the review was sourced from England, and includes some publications referring to groups other than those with disability, such as older people, where they are deemed relevant. A summary of key themes that emerged from the literature are presented below. Fully referenced discussion of each issue is included in the body of the report.

International Background

The use of self-assessment assessment in social care setting is most predominant in England. Three key developments pertaining to self-assessment there are summarised; Direct Payments, In Control and Individual Budgets Pilots. The developments undertaken by In Control have been particularly influential in the development of self-assessment in England.

The difficulty sourcing relevant information from Canada suggests that the use of self-assessment is either not widespread in Canada or that it is not generally addressed specifically in publications. It unclear how many of the provinces include self-assessment as part of their self-managed care programmes.

Literature from Australian sources seldom included specific reference to self-assessments. This was true even for very recent documents pertaining to the Governmental inquiry into disability care and support (Productivity Commission, 2010).

What is self-assessment?

The concept of self-assessment appears to be somewhat problematic. It has a range of meanings and limited evidence base with little work published clarifying its components and its applicability to those receiving community care services. Whilst there is a lack of agreement on the precise meaning of self-assessment key features of the variable definitions include:

- Service user and/or carer led
- Needs are self rather than professionally defined
- Individual's rights, wishes and goals are upheld.

The preferred definition for this report is that of Qureshi (2006) - "A process in which a person uses information about their goals, circumstances and environment as a basis for decision-making about their future actions and needs for assistance."

While self-assessment generally has been used across a wide variety of domains, published examples of self-assessment initiatives in social care settings are rare. The limited evidence suggests that, compared to other domains, self-assessment in this domain is:

- More likely to be user initiated and interpreted
- More likely to aid decision making on behalf of the user
- Substantively different from face-to-face assessment
- Relates primarily to practice and research settings
- Directed at particular groups, such as carers, older people, and people with learning difficulties
- Highly variable in its purpose, including identifying individual needs as part of a professional assessment or as an alternative to professional assessment
- Primarily located within occupational therapy services for the provision of minor equipment and adaptations, or within assessment and care management arrangements
- Predominantly paper-based, but increasingly computer or web-based.

Self-assessment tools

Self-assessment lies at the heart of self-directed support. Within the In Control model, the self-assessment questionnaire (SAQ) provides the basis for the Resource Allocation System (RAS) and it is this model that the majority of local authorities in England have adapted for their own purposes. While there are various versions of the In Control SAQ in use, all feature the domains: meeting personal care needs; relationships; community participation; work, leisure and learning; making decisions; staying safe from harm; complex needs and risks; family carer.

Those using the SAQs have expressed reservations about:

- Its simplicity and 'narrow focus'
- The risk of people underestimating the nature and complexity of their needs
- Its ability to provide enough information to understand potential risks
- A focus on the 'here and now' without enough context and background.

Paper-based assessments have predominated but are gradually being replaced or complemented by computer or web-based. However there is some evidence to suggest that the use of information technology is not a driver for change in encouraging users to self-assess, with online assessment giving rise to less satisfaction amongst service users.

Clearly, there is a significant challenge in designing a straightforward questionnaire that is:

- In plain language, practical and easy for people to use, but provides sufficient information
- Accommodates the needs of different groups
- Strength-based through the inclusion of goals and the barriers to achieving them.
- Holistic and take the needs of the person and their family into account.

Examples of SAQs can be found on numerous websites available as online only and/or paper copy for service users and carers. These range from relatively simple “check box” forms, through to those requiring a person to enter information in a number of free fields, to more lengthy and complex documents.

What is the user experience of self-assessment?

It is clear that no single form of self-assessment is suitable for all service users or types of need and central to the use of self-assessment is the question “Does this person have the capacity to do some or all of this?”

Self-assessment appears to be particularly challenging or problematic for certain groups:

- People with high levels of cognitive or affective disorder
- People with fluctuating conditions
- People with learning difficulties
- Vulnerable or frail service users

What is the user experience of self-assessment?

The limited literature concerning the measurement of user satisfaction with assessment indicates that service users view self-assessment as acceptable when they are assured of its value and if they have or can seek professional support. Generally the self-assessment forms are seen as user-centred and the processes as holistic and goal-oriented.

Results of the most comprehensive user experience survey of self-assessment show that:

- There was no difference between self or traditional assessments in terms of ease of completion, satisfaction or the collection and sharing of information
- All other factors being equal, on-line completion was the strongest predictor of dissatisfaction or difficulty with self-assessment
- Others who found self-assessment difficult included; Asian service users, people with concerns about their memories and/or individuals who rated their health low
- Males and/or people with low mood were less likely to be satisfied with their assessment (traditional or self).

With respect to carers, there are different approaches to the treatment of their needs within the main service user (self) assessment process and evidence suggests a real danger that the needs of carers can be overlooked. Many of the reported self-assessment processes do not include questions to determine what support carers provided; whether or not they were willing and able to continue providing that level of support; if they were in need of support themselves; or carers’ wishes in relation to employment, training/education and leisure activities.

What are the outcomes and effectiveness of self-assessment?

This review found very little research evidence about the effectiveness of self-assessment, particularly with regard to the costs and benefits. Overall, self-assessment appears to have the greatest utility when it complements existing processes rather than substituting them. In this way, it can contribute to the assessment and care planning processes, thereby linking with the personalisation agenda since it facilitates the users’ involvement in the assessment. In contrast, requiring the user to complete the assessment process alone could be conceived as disempowering.

In terms of cost-effectiveness, self-assessment has produced mixed results. Some initiatives have generated greater benefit at less cost, others have been more effective in terms of enhanced satisfaction, but were more costly, and others proved to be less costly but less effective. There is, therefore, a trade-off in judging the cost-effectiveness of self-assessment in policy terms, between whether efficiency savings or enhancement of the user experience is the preferred aim. The section on implementation and sustainability details a number of factors which have been identified as important in the implementation and sustainability of innovation in social care, including self assessment.

Professional roles and workforce implications

There is growing debate about the degree to which assessment might be user initiated, user-led and used directly as a basis for provision without professional involvement.

Self-directed assessment clearly implies significant changes for those currently undertaking professional assessments. However at this relatively early stage of its use the exact nature of the changes are yet to be seen. While some have speculated there will be a reduced need for care managers, in reality authorities who have introduced self-assessment are finding that they are still needed for a number of key tasks.

While some staff were open to the changes associated with self-assessment, generally the initial responses were those of suspicion, concern and resistance. Some view the term "self assessment" as misleading because in practice it usually involves some additional input from family members, friends or other professionals, who are seen by many as providing essential support.

A dilemma identified in the review was that requiring caseworkers to conduct assessments and assist with planning while they are also responsible for allocating budget amounts can create a conflict of interest that strains their relationships with clients.

It is clear from the literature that for many professionals self-assessment is a challenging concept - there are mixed views about how it might operate and about the perceived risks associated with its adoption presents. These concerns would seem to arise from lack of knowledge of the operational detail of how self-assessment works, a lack of experience with implementation and the challenge presented by the transfer of power from professional to service user.

The primary concerns about self-assessment reflected in the literature can be summarised as:

- Individuals will make frivolous or excessive demands
- People may underestimate the nature and complexity of their needs
- People will assess their needs inappropriately and 'misuse' allocated resources
- Self-assessment will become a 'token' activity
- Service users could lose important face to face contact
- Understanding how self-assessment fits with current processes and eligibility criteria
- Self-assessment will involve balancing an increased demand with a constrained budget

Implementation and sustainability

The only published study found in this review which considered implementation and sustainability of innovation in public sector social care settings concluded that there is no single recipe for successful implementation - no 'road map for others to follow'. However a number of factors were identified in the study as important in the implementation and sustainability of innovation in social care. These are detailed on pages 48-51.

Stock-take

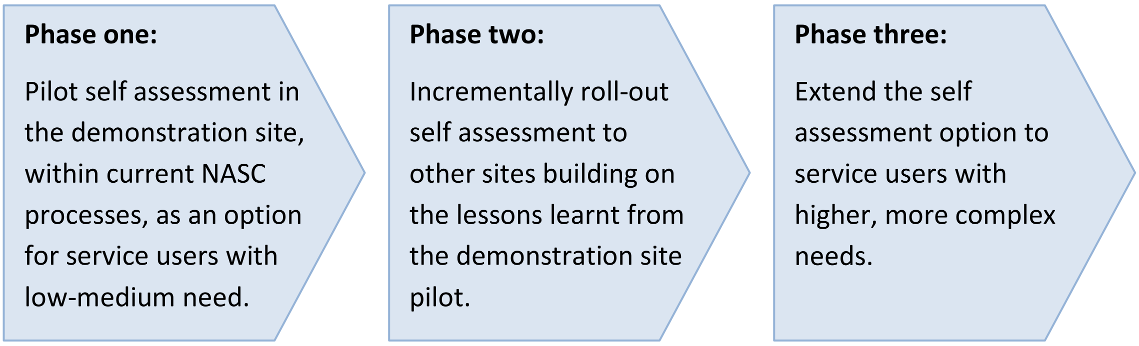
Telephone interviews were conducted with 18 NASC managers and/or senior executives from 16 NASC contracted agencies (or branches) nationwide. Only one organisation reported using self-assessment, and two utilised modified processes that included elements of self-assessment. A number of others spoke about the occasional use of 'adapted' or 'flexible' approaches to assessment that incorporated components or principles of self-assessment. Some of the more commonly shared views about self-assessment included:

- Self-assessment involves a person completing their own assessment (with or without support) and providing information from their perspective
- Whilst - current assessments are face-to-face, self-assessment would be largely independent of professional input
- Self-assessment, -as part of a self directed or self managed approach is about empowering the client and giving them more choice and control
- More emphasis needs to be placed on families, networks and the opportunities that these have to provide for support
- Self-assessment needs to use a strength-based model, including strengths, what is being managed well and future goals and aspirations.

Recommendations and discussion

The recommendations and discussion report have been informed by international experience and evidence and practical knowledge of the New Zealand DSS environment. However it should be noted that the use of self assessment in social care settings is relatively recent, it is not widespread and there is limited documented evidence about the implementation, efficacy and outcomes of self assessment, particularly as it pertains to DSS. Seven primary recommendations are made for the implementation of self-assessment in New Zealand:

1. - That self-assessment for disability support services in New Zealand is introduced in a three-phase incremental approach, as outlined in figure 1.



Phase one:

Pilot self assessment in the demonstration site, within current NASC processes, as an option for service users with low-medium need.

Phase two:

Incrementally roll-out self assessment to other sites building on the lessons learnt from the demonstration site pilot.

Phase three:

Extend the self assessment option to service users with higher, more complex needs.

Figure 1: Recommended approach to implement self assessment in New Zealand

2. - That in the demonstration site self assessment is offered to service users with low-medium need, specifically those only requiring household support, personal cares and/or minor equipment and adaptations.

3. - That preliminary to phase 1, the Ministry of Health engage with the disability community to clarify what service users are expecting self-assessment to deliver.

4. - That a self-assessment questionnaire appropriate for New Zealand is developed building on work already undertaken locally and as an integrated piece of work in the co-development of the new model involving a wide range of stake holders, including NASC, service users and carers, providers, Maori and other ethnic groups.

5. - **T**hat the self-assessment questionnaire is developed as a standard template against the New Zealand standards and criteria to ensure that these continue to be met in the self-assessment process.

6. - That initially self-assessment would be paper-based with alternative mediums offered as tools and processes are refined and validated.

7. - That the effectiveness of self-assessment is formally evaluated in the demonstration then in each site as it is incrementally implemented.

Requirements for implementing self-assessment

Informed by the literature and overseas experience the following are suggested as requirements for implementing self-assessment in New Zealand:

- Clear policy and political mandate
- A clear and agreed understanding of the purpose of self-assessment
- Close links with existing services and relevance to the wider agenda
- A partnership, co-development approach requiring active engagement of support networks and communities
- Managing the scale and complexity of change through a graduated approach with incremental shifts in practice
- Visible and ongoing senior management support and leaders who effectively engage and support staff and the wider community

- Flexibility and adaptability
- Challenging the culture – changing staff perceptions through support and engagement
- Marketing and publicity to engage with and learn from the community and to promote a culture of self-assessment
- Appropriate access to information technology and support
- A robust, independent and ongoing evaluation.

Introduction

In May 2010, the Ministerial Committee on Disability Issues considered a Ministry of Health paper outlining a new model/framework to support disabled people. The Committee agreed to the paper’s recommendations and in June 2010 Cabinet supported the decisions taken by the Ministerial Committee. The recommendations stated that the immediate focus will be on further development of the new model, including:

a. Ongoing consultation with the disability sector on the new model to support disabled people. The Ministry of Health has already begun informal discussions with interested groups on the new model and has received significant positive feedback.
b. Ongoing development of the new model, which will include addressing the policy, operational and implementation issues that it raises. For example, consideration needs to be given to what funding can and cannot be used for.
c. Demonstrating the core elements of the new model at least one or two sites. The most significant part of the demonstration projects will be introducing Local Area Coordinators. The Ministry of Health will continue with existing initiatives to allocate funding rather than supports, expand individualised funding and improve accountability arrangements but will identify opportunities to expand or extend them in the demonstration sites.

(Cabinet Social Policy Committee, 2010)

The model comprises four key components:

a. Information and Personal Assistance, including the core element of Local Area Coordination
b. Allocation of Funding, including greater use of self-assessment and moving toward allocation of indicative funding (but not entitlements) rather than by service type and level
c. Purchasing, including the expansion of Individualised Funding and moving to contracting for more flexible supports
d. Accountability, including a new accountability framework and evaluation of the Demonstration Project.

(Cabinet Social Policy Committee, 2010)

To inform the Allocation of Funding component, the Ministry commissioned a report on self-assessment models, practice and tools within disability support services, including:

a. A literature and document review of international self-assessment best-practice
b. A stock-take and analysis of self-assessment practice in New Zealand, and
c. Recommendations on design and implementation of self-assessment (for Ministry of Health funded clients with intellectual, physical and sensory disabilities who are usually aged less than 65 years).

This report is the culmination of that work and is presented in three parts: Literature Review; Stock-take; and Recommendations.

Part one: Literature Review

Background and Scope

This review seeks to explore the use of self-assessment models, practice and tools within disability support services. As there have been few published studies of the structure, process or outcome of self-assessment in this area, it also draws on work in other domains and settings where relevant.

Internationally a large volume of work has been undertaken to create self-directed, personalised options of care and support across a range of sectors, such as health, disability and aged care. Since the 1970's many initiatives have been implemented in variously configured models representing quite different approaches. These 'person centred' approaches have been central to developments in the delivery of health and social care services for people with disabilities in a number of countries including New Zealand, Australia, Canada, the United Kingdom and the USA.

Of particular relevance to the current New Zealand context and the development of the new model/framework to support disabled people, are the strategies of individualised funding (IF) and local area coordination (LAC). The Ministry of Health recently commissioned a literature review to examine the available evidence pertaining to these two strategies (Bennett & Bijoux, 2009).

It is not within the scope of the current report to review these approaches; however, the review of self-assessment models, practices and processes is closely linked to them. Any self-assessment component of these strategies is typically embedded in the larger programmatic model underpinning each strategy. As such, it is usually extremely difficult to disentangle self-assessment as a discrete item for examination (Kendrick, personal communication, 2010).

Because it is essentially part of a larger process, self-assessment is not generally singled-out as a specific programme component and has seldom been explicitly studied or evaluated. As Griffiths and colleagues (2005) note, whereas user involvement in general has been relatively well studied, self-assessment as a specific mechanism has not. Consequently references to self-assessment in the literature tend to be incidental in other published material and where self-assessment has been explicitly addressed, the discussion is frequently of a descriptive rather than analytical nature (Kendrick, personal communication, 2010).

A notable exception is the extensive evaluation study undertaken by the Personal Social Services Research Unit (PSSRU) at the University of Manchester. The PSSRU was funded by the Department of Health to evaluate the efficiency and effectiveness of self-assessment practices in adult care in 13 pilot sites in English authorities between October 2006 and November 2007. This work is represented in the review primarily by publications from Challis, Glendininng, and colleagues.

Method

A comprehensive search strategy was used to identify appropriate resources for use in this review. Documents were sourced primarily through the CCS Disability Action Information Service, Massey University Electronic Library resources and the In Control website.

Literature searches used a range of web-based databases, including:

- PubMed
- Social Care Online
- NARIC
- Clearinghouse for Home and Community Based Services
- NHS Evidence Specialist Collections
- Centre for Reviews and Dissemination – University of York
- CCS Disability Action Library Catalogue
- Massey University databases:
    - Google Scholar
    - Academic Search Premier
    - Medline

Searches used identified country specific keywords and combinations of the search terms were used for searches of material:

Search terms:

- assessment&(service delivery/disability services)
- self-assessment” disability services
- “self-assessment” AND disability support
- self-assessment questionnaire
- “user led assessment” +disability
- user defined assessment
- citizen directed support
- user conducted assessment
- consumer controlled self-assessment
- consumer directed self-assessment
- individualized funding
- self directed support/care
- “direct funding” disability assessment
- consumer directed programme
- “financing, personal” AND “disabled persons”

Searches were also guided by particular types and formats of information, including policy and procedural documents, outcomes and stories from people who have already gone through self-assessment for disability services (formal and non-formal), existing self-assessment tools, and examples of forms and questionnaires.

There were a number of organisations requiring further research, both online and with personal contacts, as they were known by the researchers to work in the disability services field. This included:

- Social Care Institute for Excellence (UK)
- Personal Social Services Research Unit (PSSRU), University of Manchester (UK)
- In Control (UK and Australia)
- Roeher Institute (Canada)
- Social Policy Research Centre, University of NSW
- Aging and Disability Resource Center (US)
- Individuals - Michael Kendrick, Eddie Bartnik, Simon Duffy, David Challis, Karen Fisher, Christian Bland, Alison Barber.

Grey literature was sourced with web searches and searching references cited in key articles and reports. Grey sources of information include the FADE Library (NHS), Networked Digital Library of Theses, Quality Mall, Human Services Research Institute, National Association of State Director of Developmental Disabilities Services, Center on Human Policy, and Family Advocacy.

The literature review also considered the following when setting up the search strategy:

- Currency – documents published from 2000 onwards
- Source – a reputable and known researcher and research organisation
- Unknown sources were traced to origin and authenticity confirmed
- Reliability and relevance – all resources were reviewed by the researchers to ensure they were appropriate to the project's purpose
- Language – English
- Coverage – Australia, UK, USA, Canada, Europe

Comments on the literature searching

- The most difficult process in reviewing results from the literature searches was that 'self-assessment' was not often identified as a distinct step in the process of obtaining services and where is was, was rarely investigated by researchers as a separate entity to other processes
- There was very little material on 'self-assessment' in the Canadian context – most assessment procedures were only allowed to be completed by professionals with little independent user comment. We could only find two programmes that used a consumer based assessment model - Ontario's Self Managed Attendant Service Funding Programme and Manitoba's In the Company of Friends
- Searching for "self-assessment AND disability services" in Australia and the UK leads to information resources on the self-assessment of disability services and organisation by service users.

As a consequence of these limitations in the available literature, much of the material used for this review was sourced from England, and includes some publications referring to groups other than those with disability, such as older people, where it was deemed to be relevant.

International Background

Three approaches to the assessment of need and resource allocation in consumer-directed care projects can be identified in the literature (Laragy.& Naughtin, 2009). The first and most common approach is allocate funds following and according to a professionally assessed level of need. A second approach is to develop with the consumer a plan that is later costed. Self-assessment is the third approach recently trialled in England. In this literature search, few direct references to self-assessment processes were found outside of the English experience.

England

As noted above, much of the literature sourced for this review relates to developments in social care in England. Whilst it is not within the scope of this review to describe these changes in detail, a brief summary of three key initiatives provides a context for the following discussion.

Direct payments

Direct Payments were introduced in 1997 and allowed local authorities to make cash payments, or a combination of cash and services, to people eligible for social care in lieu of local authority commissioned social services. Initially this applied only to disabled people aged between 18 and 65 who were willing and able to take responsibility for their own care arrangements. From 2000, eligibility was extended to people aged over 65, and from 2001 to carers, parents of disabled children, and to 16-17 year old young people. Since 2003, there has been a duty on local authorities to offer Direct Payments to people eligible for social care (Hudson & Henwood, 2009).

In 2006-07 Direct Payments accounted for 7% of net expenditure on community services (Hudson & Henwood, 2009) and although the number of people receiving direct payments more than doubled from an estimated 15,000 in 2003 to 37,000 in 2005, direct payment users still represent only 2.5% of all adults receiving community-based social care services in England (Glendininng, et al., 2009). Take up of direct payments remains patchy both geographically and with variation between different user groups (Hudson & Henwood, 2009).

In Control

Established as a social enterprise organisation in 2003, In Control conceived and developed the concept of a “personal budget” to use within a new model of active citizenship and self-directed support. Local authorities can join In Control as members, and the vast majority have done so (122 out of 150 in 2009) (Hudson & Henwood, 2009).

The In Control approach encourages self-assessment; the allocation of resources to individuals according to relative levels of need; transparency about the resources allocated to each person; and support in planning how to use those resources to meet individual priorities (Glendininng, et al., 2009). In Control encourages flexibility and the use of a wide range of ordinary community-based services and supports and has a broad aim of redesigning social care systems towards ‘self-directed support’ (Duffy, 2004; 2005). Boxall et al. (2009) describe the In Control model as exceptional, and probably unique, among individualised funding initiatives in attempting to create a system based on early awareness of financial entitlement, with the individual budget (IB) determined at the outset on the basis of a score from self-assessment.

Individual Budget Pilots

In November 2005, it was announced that IBs were to be piloted in 13 sites across 11 English local authorities between 2006 and 2008 for: people with physical or sensory impairments, learning disabilities, mental health needs and older people (Glendinning et al., 2009).

Three research units collaborated to evaluate the pilots (known as the IBSEN project – the Individual Budgets Evaluation Network) – the Personal Social Services Research Unit (LSE, University of Manchester and University of Kent), the Social Care Workforce Research Unit (King's College, London) and the Social Policy Research Unit (University of York). The central aim of the evaluation was to identify whether IBs offer a better way of supporting disabled adults and older people than conventional methods of resource allocation and service delivery; and, if so, which models work best for which groups of users (Hudson & Henwood, 2009).

Although there is some variation in how they are conceived, IBs have generally been defined as a sum of money allocated to eligible individuals for them to decide to spend as they wish in order to provide the 'package of support' they want (Boxall et al., 2009). Two key characteristics of IBs include that they may include funding from a range of funding streams and that through a 'resource allocation system' (RAS) service users very quickly know what their entitlement is.

The IB can be used to secure a flexible range of goods and services, from a wider range of providers, than was possible through either direct payments or conventional social care services. For example, an IB may be used to pay informal carers (including close relatives living in the same household), or to purchase goods or services from local authorities – opportunities not normally available to users of direct payments (Glendining, 2008).

While 'personal budgets' of the type pioneered by In Control had focused on social care funding, the IB pilots attempted to bring together additional funding streams (Access to Work; Independent Living Fund; Supporting People; Disabled Facilities Grant; local Integrated Community Equipment Services)(Hudson & Henwood, 2009).

Most of the pilot sites have variants self-assessment questionnaires developed by In Control, and service users are completing the forms with help from their care manager, support worker, family or friends. Some sites, however, still regard self-assessment as too risky. (Henwood & Hudson, 2007a).

Canada

In Canada, home care programmes have been funded by Canadian provinces for over three decades. Home care refers to the provision of health and social services designed to support living at home for those who are ill, disabled, or dying (MacAdam, 2004). The programmes are similar across Canada in a number of features: entry to all home care services is by way of a provincially designated public or quasi-public agency, eligibility for any type of home care is based on needs as determined by a provincially uniform assessment and care planning process, all provinces offer a case management service, and all have a single provincial or regional administrative structure (MacAdam, 2004).

In 2004, seven provinces and one territory (Quebec, British Columbia, Alberta, Ontario, Manitoba, New Brunswick, Newfoundland, and the Northwest Territories) offered self-managed care models of care in addition to traditional provider models (MacAdam, 2004).

Spalding and colleagues (2006) identified 16 documented self managed home care programmes in which clients are directly funded to purchase services from providers of their choice. The programmes vary significantly in terms of the population served, degree of self determination, and funding mechanism. The range of clients using self managed home care programmes include; children and families with continuing care needs, adults with physical disabilities, adults with chronic illnesses, and adults with developmental disabilities.

However it is unclear how many of the provinces include self-assessment as part of the programmes. Spalding and colleagues (2006) noted that there was considerable variation in the process of assessing eligibility and needs. In some programmes, assessment was undertaken by professionals, in others, consumers have a more active and participatory role, but it does not appear that any of these could truly be described as self-assessment.

The Public Health Agency of Canada funded a project initiated by the Kendrick Report Coalition (KRC) to investigate best practices for two alternatives to traditional forms of disability supports: self-management and supported decision-making. The project included a literature review of programmes in Canada and internationally, and consultation within Nova Scotia (KRC, 2005). The authors commented that

> A unique feature of the Ontario self-management program delivered by the Centre for Independent Living in Toronto (CILT), lies in the selection process which emphasizes self- assessment by having individuals define the types of services required, create budgets and demonstrate self-management ability (KRC, 2005, p.4).

This comment suggests that the use of self-assessment is either not widespread in Canada, or it may be that it is simply not addressed specifically in publications. In a recent report which included a review of seventeen funding models in Canada and internationally, Chopin and Findlay (2010) described programmes across the provinces, including the range of assessment practices. No mention was made, however, of self-assessment.

The CILT self-assessment for Direct Funding is not particularly user-friendly with a strong focus on budget planning and funding (http://www.cilt.ca/funding_app.aspx).

Australia

Literature from Australian sources seldom included specific reference to self-assessments. This was true even for very recent documents pertaining to the Governmental inquiry into disability care and support (Productivity Commission, 2010).

In 2010, the Australian Government asked the Productivity Commission to undertake a "public inquiry into a long-term disability care and support scheme and advise on a scheme that will cover those most in need, with a disability present at birth, or acquired through an accident or through a health condition, but not as a result of the natural process of ageing” (Productivity Commission, p.1).

Consumer Directed Care is planned for all Australian Government funded Packaged Care Programmes. The model is an individual budget based on a needs assessment and administered on the care recipient’s behalf for an agreed percentage of the allocated budget (Department of Health and Ageing, 2010). It is questionable whether self-assessment has a role in this new model. The information document clearly states that an individual budget will be based on a “care recipient’s needs as assessed by the packaged care provider” (Department of Health and Ageing, 2010, p. 5).

The Australian Federation of Disability Organisation (AFDO) submission also suggests that self-assessment is not a common component in Australian processes. They propose that “the main goal of assessment should be letting the person with disability provide information. If the person needs assistance to do this, they should be given the choice to nominate a support person, who should be as independent as possible from the outcome, such as a friend or family member, and not a care worker or service manager. Formal assistance should also be available for those who request it” (AFDO, 2010, p.).

Even the In Control Australia submission to the Productivity Commission inquiry into disability care and support has little to say about self-assessment beyond that the eligibility for the new scheme must be assessed by a framework which has the capacity to stand as a framework for the development of self-assessment and monitoring/appeals tools (In Control Australia, 2010).

In the absence of clear evidence to the contrary, it appears that self-assessment does not have a key role in Australian disability care and support programmes.

What is self-assessment?

The process of assessment, is the collection of information on people’s specific needs, problems and preferences, is central to the planning and delivery of social care and health services in the widest sense (Challis et al., 2009). Ensuring that the process is personalised and accessible is “important in terms of both individuals’ experiences and resource allocation, providing the basis on which needs are identified and services are commissioned” (Challis et al., 2008b, p.4).

The “Personalisation” and ‘Self Directed Support’ agenda are progressing rapidly (Clements et al., 2009) and require new ways of assessing people in order to offer a greater degree of choice, control and individually tailored approaches to people who may require personal support or assistance (Cm 6737, 2006). The principle that people should be supported to identify their own needs is the starting point for self-directed support, and is a fundamental principle that gives practical effect to the idea of transferring power from the professional to the service user and their carers (Henwood & Hudson, 2007b). John Waters of In Control recognises this challenge, commenting that self-assessment is possible but that it requires professionalism to let go of power and control. Further, that it:

> ...threatens professional power and there is a cultural challenge to accept a system based on trusting disabled people. In the UK 'assessment' is the only legal entitlement for a citizen and duty for the govt, in relation to social care, so

> without replacing these with better alternatives...there is a risk that a shift towards self-assessment erodes statutory protection (John Waters, personal communication, 2010).

Although self-assessment has been identified as a key mechanism to achieve greater involvement of service users as active participants in health and social care (Griffiths et al, 2005), little agreement on the precise meaning of the term emerges from the literature. Occasionally used to simply refer to self-report, self-assessment has been variously defined as:

- Service users and carers undertaking the assessment, usually applying predetermined processes and criteria (Whittington, 2007)
- Assessment that is completed by the subject of the assessment without the immediate involvement of professionals' (Griffiths et al, 2005)
- The idea that an individual controls the assessment of their need for social care support (Clements, 2008)
- Locating the individual at the heart of their assessment with their rights, wishes and goals upheld, with a notion that needs are self rather than professionally defined (Clarkson et al., 2010)
- Assessment undertaken by disabled people of their own needs. The principle underlying this process is that disabled people understand their own needs better than social workers (Renshaw, 2008)

The following definition is preferred for the purposes of this report:

> A process in which a person uses information about their goals, circumstances and environment as a basis for decision-making about their future actions and needs for assistance (Qureshi, 2006, p1.)

As Challis et al. (2008c) note, this definition contains both the perceived potential benefits of self-assessment, that it may help in assisting the person to clarify goals that are important to *them*, and also the difficulties and complexities, that the *decision-making* function of assessment leads to challenges in terms of who is required to make the decisions regarding resource allocation.

The concept of self-assessment appears to be somewhat problematic. It has a range of meanings and limited evidence base with little work published clarifying its components and its applicability to those receiving community care services (Griffiths et al., 2005; Qureshi, 2006).

Self-assessment generally has been used across a wide variety of domains and for a number of purposes ranging from targeted screening for specific medical disorders through to approaches designed to help individual decision-making in relation to major life events such as changing accommodation (Griffith, 2005). However much of the literature has focussed on the use of case-finding in general practice and has been undertaken within the tradition of research enquiry (Challis et al., 2010).

Self-assessments can be categorised according to their content in relation to health and social care and according to the extent to which they focussed on single or multiple problems. They can be located at various points in the assessment process (Challis et al. 2008b) and potentially might directly substitute for, prepare for, be a part of, or be subsumed into, professional assessment (Qureshi, 2006).

In their review of the use of self-assessment Griffiths et al. (2005) found that in the majority of *focussed* health related assessments, self-assessment substituted for professional assessment, and in most cases was simply a mode of administering a screening test without having face-to-face contact. Most self-assessments in health were professionally initiated and interpreted (Griffiths, et al., 2005).

Although fewer in number, there is more variety in the *general* health assessments identified by Griffiths et al. (2005). Examples include paper and pencil questionnaires, self-assessment algorithms and web-based systems with feedback. There was more autonomy in the use of the assessments, with some examples being entirely user directed from initiation to action. Frequently the goal was to improve management of healthcare in general and to mediate relationships with professionals (Griffiths, et al., 2005).

While published examples of self-assessment initiatives in social care settings are rare, Challis et al. (2008c) identified a number of recurrent themes within the emerging literature. They found more variety and reported that many of the examples identified were substantively different from face-to-face assessment. They found that self-assessments in this domain are more likely to be user initiated and interpreted and to aid decision making on behalf of the user.

The use of self-assessment in social care settings relates primarily to practice and research settings and has been directed at particular groups. The focus of interest has been on carers, older people as part of the Single Assessment Process (SAP) (Griffiths et al., 2005) and people with learning difficulties through the In Control programme of self-directed support (Duffy, 2004; 2005).

The function of self-assessments varies, with a number related to the carer role, such as to assess carers' needs, help practitioners support carers, identify carers requiring professional assessment and to help carers prepare for professional assessment (Challis et al., 2008c). The purpose of most self-assessment within SAP was to identify individual needs as part of a professional assessment. Other tools, such as EASY-care (Philp, 2000 as cited in Challis et al., 2008c) and the Cambridgeshire Assessment Tool (Purdie, 2003 as cited in Challis et al., 2008c) were piloted as alternatives to professional assessment. The Knowsley Overview Assessment was designed to be wholly self completed (Moss, 2003, as cited in Challis et al., 2008c). In each of these cases, it is the professional who initiates, interprets and acts upon the assessments (Challis et al., 2008c). In contrast, the developing models of self directed support for disabled people enable people to both assess their own needs and develop their own support plans (Challis et al., 2008c).

The location of self-assessment also varies. Within SAP and self-directed support initiatives, self-assessments sit within assessment and care management arrangements, others are located within occupational therapy services. Indeed as Challis et al. (2008c) point out, the use of self-assessment in the provision of minor equipment and adaptations has attracted considerable attention and a number of councils offer a restricted range of services on this basis.

Internationally this is probably the most common use for self-assessment in the social care domain.

Paper-based assessments have predominated but are gradually being replaced or complemented by computer or web-based approaches (Challis et al., 2008c; Whittington, 2007). There are two internationally recognised online assessment systems, the Self-assessment Rapid Access (SARA: AskSara website) and the ADL Smartcare (ADL Smartcare website). Through both systems individuals are able to assess their need, and access information on simple pieces of equipment, initiating, completing and acting upon the assessment themselves. Both are discussed in more detail later in the report.

The potential benefits of user self-assessment have also been noted in the literature. Whittington (2007) suggests the following possible gains:

- Recognising and using the expertise of service users and carers
- Challenging cultural values about the dependency of particular groups
- Guiding people to sources of help and clarifying eligibility
- Where online methods are used, providing 24-hour access to assessment
- Providing an early alert to need
- Speeding up provision by removing the wait for professional assessment
- Enabling service users to prepare for professionally conducted assessment
- Obtaining an evaluative check on services currently being used.

(Whittington, 2007, p.48)

Similarly, Qureshi (2006) maintains that self-assessment recognises and makes use of the expertise of service users, and, sometimes, family carers and that where a person is receiving, or may need, services, self-assessment has the potential to:

- Direct people to suitable/appropriate sources of assistance and give them information about eligibility
- Bypass the need for professional assessment and thus speed up provision
- Enable -service users to prepare for a professional assessment, potentially thus increasing their level of involvement and influence
- Enable service users to evaluate the outcomes and process of their existing services.

(Qureshi, 2006, p.1)

Self-assessment tools

The way in which potential users are assessed for support is an important influence on self-determination. It is a complex issue and is central to the debate on user control and empowerment.

Self-assessment lies at the heart of self-directed support and, within the In Control model, the self-assessment questionnaire (SAQ) provides the basis for the RAS (Henwood & Hudson, 2007b). In Control created a prototype SAQ that they made available for authorities to adapt for their own purposes. Whilst most authorities start with a different SAQ for different groups, the aim is to get a single self-assessment system that does not distinguish between groups (Browning, 2007).

Within the IB pilots, different models are being trialled and there are various SAQs in use, but all feature a number of 'domains' or areas of life. Each domain is then divided into 'fields', which reflect different abilities within each domain. Each field is scored, and the greater the need, the higher the number of points allocated (Browning, 2007). The In Control Fact Sheet describes the domains as:

- Meeting personal care needs – looking after yourself: for example, eating, washing, dressing, shopping
- Relationships – family, friends, people you know
- Being part of the community – for example, using local shops, the library, clubs, community centre, church or other place of worship, helping neighbours, being involved in local organisations
- Work, leisure and learning – having a job, learning new things and enjoying life
- Making decisions – who decides important things like where you live, who supports you, who looks after your money
- Staying safe from harm – for example, when you're going out on a bus, using a gas cooker, or going down stairs
- Complex needs and risks – can your behaviour be dangerous for you or other people?
- Family carer – if someone in your family supports you, what effect does supporting you have on them?

(In Control Fact Sheet 3)

The experience of three localities is described by Henwood and Hudson (2007b) who undertook in-depth qualitative case studies to investigate the progress of implementing self-directed support (SDS). SAQs went through various iterations and were tested out in desktop exercises and planning live sessions. In the IB pilot site, in line with the requirements of the IB evaluation , people were allocated to IBs on a randomised basis, elsewhere the new approach to SDS was being phased in, starting with clients being reviewed but with an expectation of subsequently rolling the system out to new people entering the social care system (Henwood & Hudson, 2007b).

Evidence suggests that funders and service providers struggle with developing and implementing an assessment process for IF (Lord Hutchison, 2003). In a study of five of the English councils, Henwood and Hudson (2009) found that none had a settled approach to the SAQ and most expressed reservations about the accuracy of such assessments. One council, using a very early version of SAQ as part of an In Control pilot, concluded that the exercise had not generated a clear understanding of needs. Specifically, the evaluation of this pilot found that the SAQ:

- Did -not provide enough information about the person, leading to difficulties in reconciling the SAQ with Fair Access to Care Services (FACS) criteria
- Did - not provide enough information to understand potential risks, thereby compromising the 'duty to care'
- Focused on the 'here and now' without giving context and background.

(Henwood & Hudson, 2009)

Those using more recent versions of SAQ also had reservations, especially professionals who often compared it unfavourably with their own professionally led procedures. A particular concern was that people using services would underestimate the nature and complexity of their needs. Others thought the main problem with the SAQ was its simplicity, especially in responding to people with more complex needs. Service users in the study expressed concerns about the "narrow focus" of the SAQ and felt that it had been "lifted from the learning disability field" (Henwood & Hudson, 2009).

> "I'm not happy with the assessment form. It's lifted from the learning disability field so there's a lot of stuff around supervision, monitoring, safety issues and questions around that. There aren't actually that many questions around other things." (Person using services) (Henwood & Hudson, 2009.

The potential for increased internet access to facilitate user involvement in assessment has been recognised, however, Loader et al. (2007) suggest that this could further privilege already advantaged service users. In user-centred services increasingly driven by technology and the ability to understand and navigate information systems, there could be an uneven distribution of provision based upon technological access and confidence rather than assessed need.

Within the self-assessment projects overall, the use of information technology was not as successful or important as had initially been anticipated. It was most successful when employed in conjunction with a person. Generally speaking, information technology was not a driver for change in encouraging users to self-assess. In fact, people accessing online assessment were significantly less satisfied, except where there was a personal mediator involved interpreting the findings of the assessment into appropriate service provision or identifying the need for a professional assessment. Self-assessment alone can only provide a service response from a 'set menu'. A response which has been determined by an assessor is more tailored to individual needs and circumstances (Challis et al., 2008b).

Clearly there is a significant challenge in designing a straightforward questionnaire that is easy for people to use, but provides sufficient information; and accommodates the needs of different groups. A key learning from In Control was to "keep the whole thing simple so people can understand it and the assessment is viewed as fair by the person their family" (Waters, Personal communication). The In Control SDS fact sheet states that the self-assessment form:

- Should be practical and easy to answer
- Must take the needs of the person and their family into account
- Should make clear what outcomes the local authority expects you to achieve if you have the right support
- Should tell you if you are entitled to other kinds of funding
- Should trigger a benefit check, so you can make sure you are getting everything you are entitled to.

(In Control Fact Sheet 3)

Similarly, community consultation in Nova Scotia (Wallace, 2005) indicated that people want assessments that are; in plain language, individualised and based on wants and needs, holistic (focused on all aspects of a person's life), and used to inform the provision of flexible services, and seamless supports between life transitions.

Further more, Browning (2007) suggests that different scoring systems may be needed for different groups (people with mental health problems, and people with physical or learning disabilities) as issues that may be important for one group may be less so for another. Whether there should be different versions of SAQs to address different client groups is, however, a matter of on-going debate. Henwood and Hudson (2007b) found that even it if was decided to use a unified SAQ, this did not necessarily lead to comparable allocations under the RAS, which raises major questions about equity between different needs.

Examples of Self-Assessment Questionnaires

Examples of SAQs or SSAQs (supported self-assessment questionnaires) can be found on numerous websites. Some SAQs are available online only, some as paper copy only and others as both. In a number of instances, websites also provide carers SAQs. The assessment tools range from relatively simple 'check box' forms, to those requiring a person to enter information in a number of free fields, through to more lengthy and complex documents, such as the 40 page Tennessee Personal Assistant Supports and Services Self-Assessment Tool used in the needs assessment process for people requiring the support of a personal assistant to remain in their home (PASS, 2004).

The following are selected examples representing the types of SAQs currently in use. Whilst most will contain questions that may not be appropriate for the New Zealand context, they do provide useful options for review. The accompanying website links were correct at the time of this report going to print. Sample extracts are provided for some of the questionnaires, others are presented in full as appendices.

Online assessments for equipment and/or advice can be found on various English council websites, including a number utilising the AskSARA website. To date at least 11 Local Authorities in England have licensed AskSARA to use in their area, primarily in occupational therapy services. The London Borough of Croydon, for example, uses a customised versions of SARA "that asks a series of questions about your daily life and the difficulties you are having, and gives you tips and information on equipment and minor adaptations to your home" (http://www.croydon.gov.uk/healthsocial/disabilities/equip/sara).

AskSARA is designed primarily for individuals whose situation is not complicated and disability not severe. In Croydon, council services such as meals on wheels, home care, day services or short breaks are not covered by the self-assessment. AskSARA is a simple, highly visual online tool which steps the user through a series of screens under three main headings: Your health, Your Home, and Daily activities. Through a personalised report based on an individual's responses to the questions, product information and advice is provided to help individuals independently manage their disability needs. The website gives the example -"if having a handrail by your front door would be helpful, or if you are having difficulty getting in or out of the bath, the assessment will generate tips and information on where you can see, try and buy suitable equipment."

The estimated time for completion is about 30 minutes for most users. Those who wish to complete the online SARA self-assessment but are unfamiliar with computers or who have difficulty accessing the internet (including those for whom English is not the first language and for people with dyslexia) are provided with assistance through Age Concern Croydon.

The following screen samples illustrate the simplicity and highly visual nature of the tool. Starting from the home screen, "Preparing meals, eating and drinking" was selected then "Opening jars, tins, packages or bottles." In this manner individuals identify the tasks and activities with which they need assistance. The report is then generated to provide information and advice specific to those issues.

Your browser is no longer supported. Please upgrade to a modern browser.
Some AskSARA features may not work on this browser.

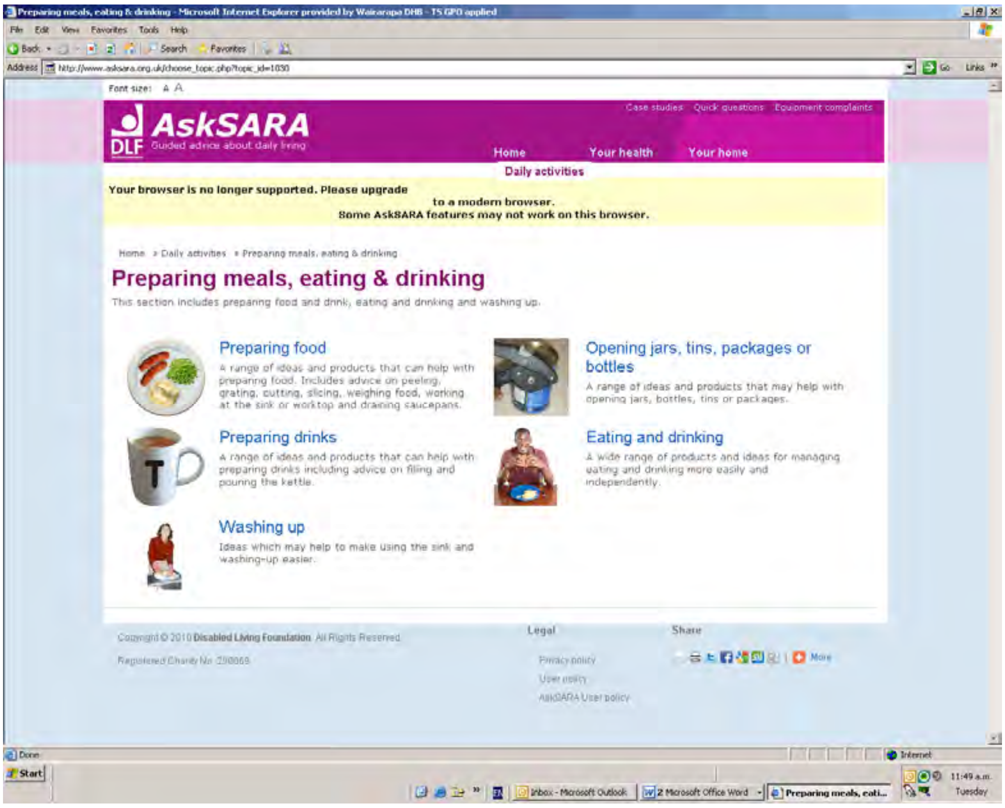
AskSARA helps you find useful advice and products that make daily living easier

Since 2010 21,416 people have answered 289,401 questions, receiving 145,963 reports!

Your health
Products and ideas on a range of physical and mental health topics

Your home
Products and ideas which may help you complete tasks in a number of household locations

Daily activities
Products and ideas which may help with a range of daily activities



Your browser is no longer supported. Please upgrade
to a modern browser.
Some AskSARA features may not work on this browser.

Home > Daily activities > Preparing meals, eating & drinking

Preparing meals, eating & drinking

This section includes preparing food and drink, eating and drinking and washing up.

Preparing food
A range of ideas and products that can help with preparing food. Includes advice on peeling, grating, cutting, slicing, weighing food, working at the sink or worktop and draining saucepans.

Opening jars, tins, packages or bottles
A range of ideas and products that may help with opening jars, bottles, tins or packages.

Preparing drinks
A range of ideas and products that can help with preparing drinks including advice on filling and pouring the kettle.

Eating and drinking
A wide range of products and ideas for managing eating and drinking more easily and independently.

Washing up
Ideas which may help to make using the sink and washing-up easier.

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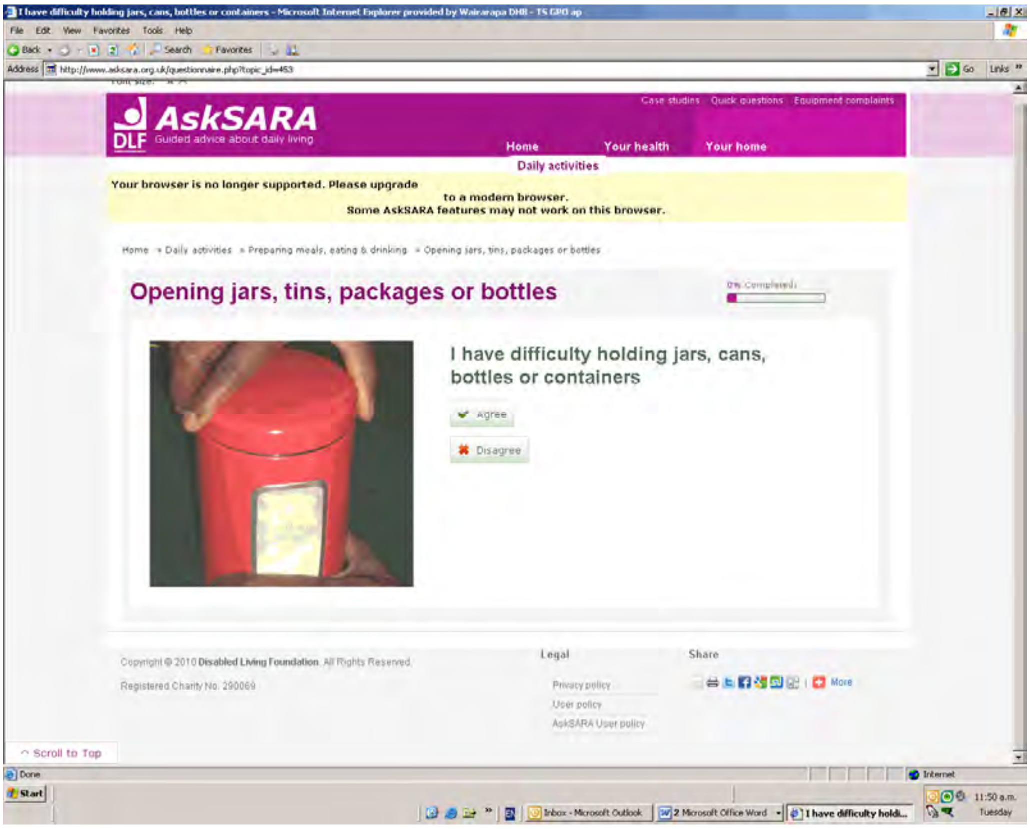
Registered Charity No. 290069


I have difficulty holding jars, cans, bottles or containers - Microsoft Internet Explorer provided by Wairarapa DHB - TS GPO ap

http://www.asksara.org.uk/questionnaire.php?topic_id=453

Your browser is no longer supported. Please upgrade to a modern browser.
Some AskSARA features may not work on this browser.

Home » Daily activities » Preparing meals, eating & drinking » Opening jars, tins, packages or bottles

Opening jars, tins, packages or bottles

0% Completed

I have difficulty holding jars, cans, bottles or containers

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Registered Charity No. 290069

Like Croydon, the London borough of Kingston is one of 11 self-assessment pilot sites for people with long-term social care and health needs. Kingston offers disabled and older people the chance to assess themselves for small items of daily living equipment through the online SmartAssist self-assessment tool (ADL Smartcare website). Kingston Council introduced the online self-assessment service as an additional point of access for local services, rather than as a replacement for traditional ways of accessing services.

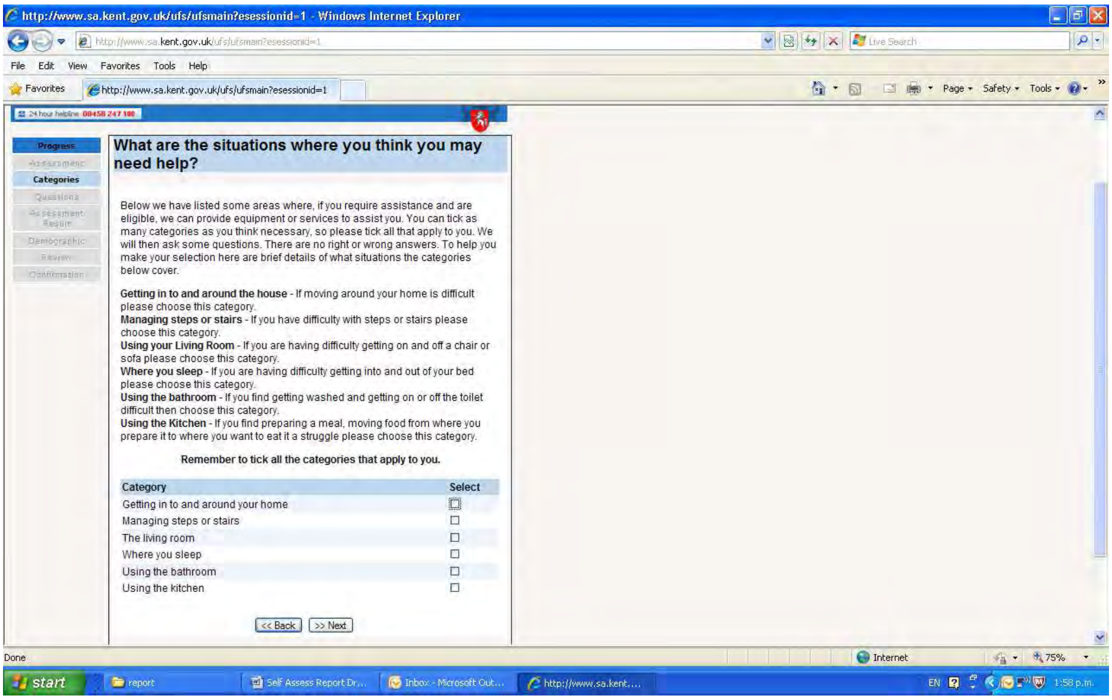
SmartAssist is primarily equipment related and gives individuals the ability to self-assess for aids to daily living, such as raised toilet seats, bath boards, tap turners etc. Individuals can assess a number of problems by answering three areas of questions and receiving detailed product information matching their specific requirements. Details of where to order/purchase the products are also given.

A number of councils use SmartAssist which is accessed through a common portal - http://www.self-assess.co.uk/saportal. Users must be resident in the council concerned and have to register on the website before progressing through the self-assessment. This is likely to be a deterrent for some people. Whilst this is also a highly visual and relatively simple tool, it is more difficult to navigate than AskSara and appears to have a narrower focus.

You are assessing for yourself. Please select an area of the home you are having the greatest difficulty with:

In a similar vein, Kent County Council's website offers two types of self-assessment online; a General Needs assessment for adults who are finding it difficult to manage everyday activities, and a carer assessment to enable a person to assess their needs as a carer.
www.kent.gov.uk/adult_social_services/your_social_services/advice_and_guidance/assess_your_needs_online.aspx

The general self-assessment allows people to determine their eligibility for support, and if eligible, to select from a range of equipment matched to their needs.
http://www.sa.kent.gov.uk/ufs/ufsmain?esessionid=1&RG=GR1112&formid=SAP&esessionid=1
The questionnaire starts with an indication of the key domains people may be having difficulty with then progresses through series of screens asking for greater detail, including general health questions. On the basis of the responses given, a report is produced which details the services and/or equipment the individual may be entitled to.



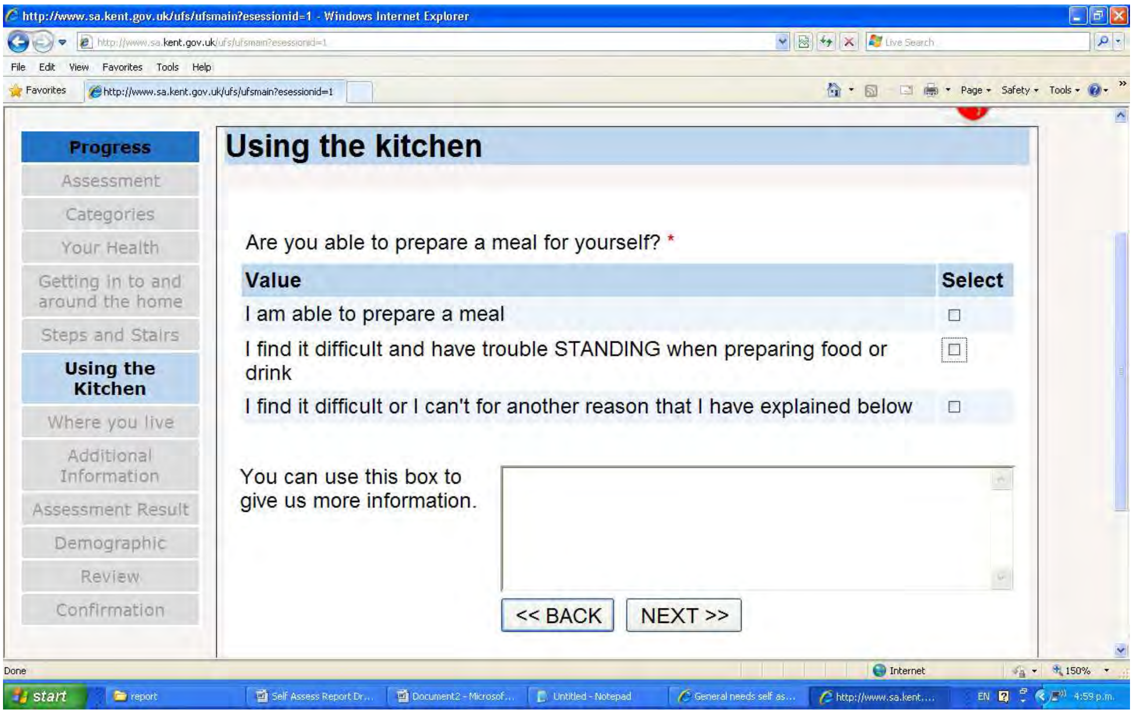
What are the situations where you think you may need help?

Below we have listed some areas where, if you require assistance and are eligible, we can provide equipment or services to assist you. You can tick as many categories as you think necessary, so please tick all that apply to you. We will then ask some questions. There are no right or wrong answers. To help you make your selection here are brief details of what situations the categories below cover.

Getting in to and around the house - If moving around your home is difficult please choose this category.
Managing steps or stairs - If you have difficulty with steps or stairs please choose this category.
Using your Living Room - If you are having difficulty getting on and off a chair or sofa please choose this category.
Where you sleep - If you are having difficulty getting into and out of your bed please choose this category.
Using the bathroom - If you find getting washed and getting on or off the toilet difficult then choose this category.
Using the Kitchen - If you find preparing a meal, moving food from where you prepare it to where you want to eat it a struggle please choose this category.

Remember to tick all the categories that apply to you.

Category	Select
Getting in to and around your home	☐
Managing steps or stairs	☐
The living room	☐
Where you sleep	☐
Using the bathroom	☐
Using the kitchen	☐

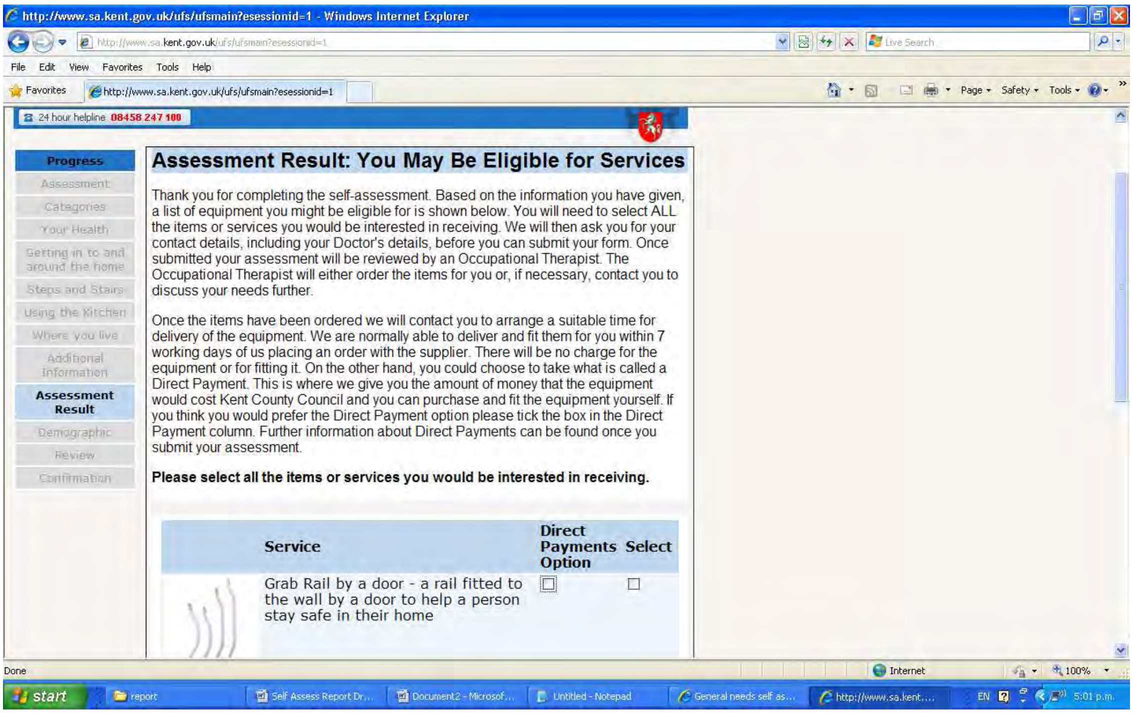


Using the kitchen

Are you able to prepare a meal for yourself? *

Value	Select
I am able to prepare a meal	☐
I find it difficult and have trouble STANDING when preparing food or drink	☐
I find it difficult or I can't for another reason that I have explained below	☐

You can use this box to give us more information.



Assessment Result: You May Be Eligible for Services

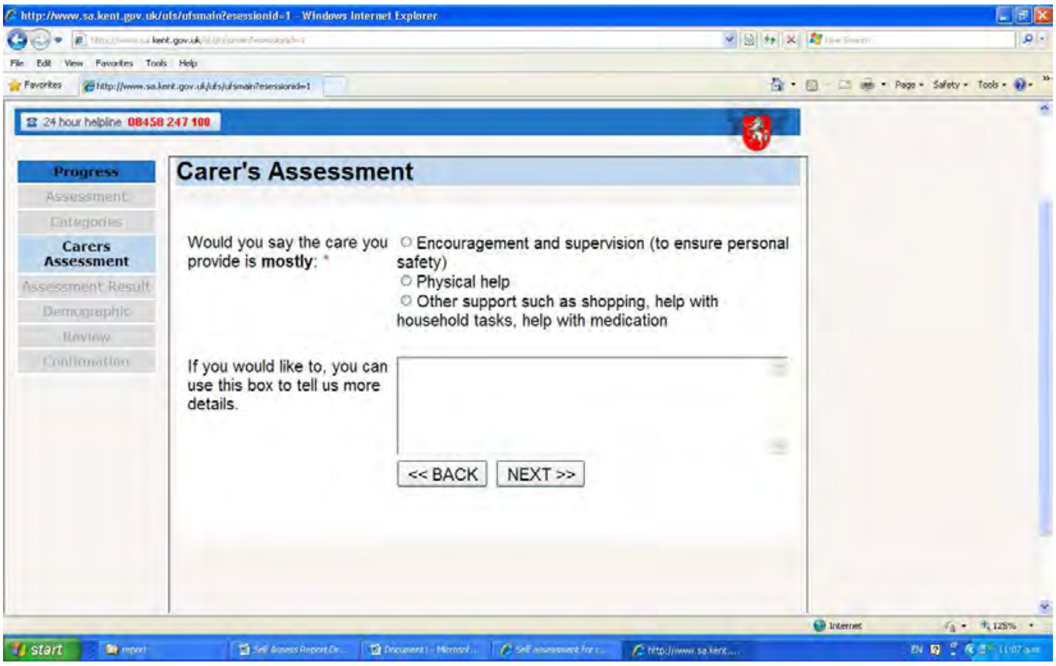
Thank you for completing the self-assessment. Based on the information you have given, a list of equipment you might be eligible for is shown below. You will need to select ALL the items or services you would be interested in receiving. We will then ask you for your contact details, including your Doctor's details, before you can submit your form. Once submitted your assessment will be reviewed by an Occupational Therapist. The Occupational Therapist will either order the items for you or, if necessary, contact you to discuss your needs further.

Once the items have been ordered we will contact you to arrange a suitable time for delivery of the equipment. We are normally able to deliver and fit them for you within 7 working days of us placing an order with the supplier. There will be no charge for the equipment or for fitting it. On the other hand, you could choose to take what is called a Direct Payment. This is where we give you the amount of money that the equipment would cost Kent County Council and you can purchase and fit the equipment yourself. If you think you would prefer the Direct Payment option please tick the box in the Direct Payment column. Further information about Direct Payments can be found once you submit your assessment.

Please select all the items or services you would be interested in receiving.

Service	Direct Payments Option	Select
Grab Rail by a door - a rail fitted to the wall by a door to help a person stay safe in their home	☐	☐

Kent County Council's carer self-assessment is very similar to that for service users. Through a series of screens, the carer is asked questions about the person or persons they care for, the type of care provided, and if they feel that they can continue to provide it. As the following sample screens illustrate, the carer selects the answer that most describes their situation and can, in some instances, provide more detail in a free text box.



Carer's Assessment

Would you say the care you provide is **mostly**: *
○ Encouragement and supervision (to ensure personal safety)
○ Physical help
○ Other support such as shopping, help with household tasks, help with medication

If you would like to, you can use this box to tell us more details.

Assessment Result: You may be eligible for services

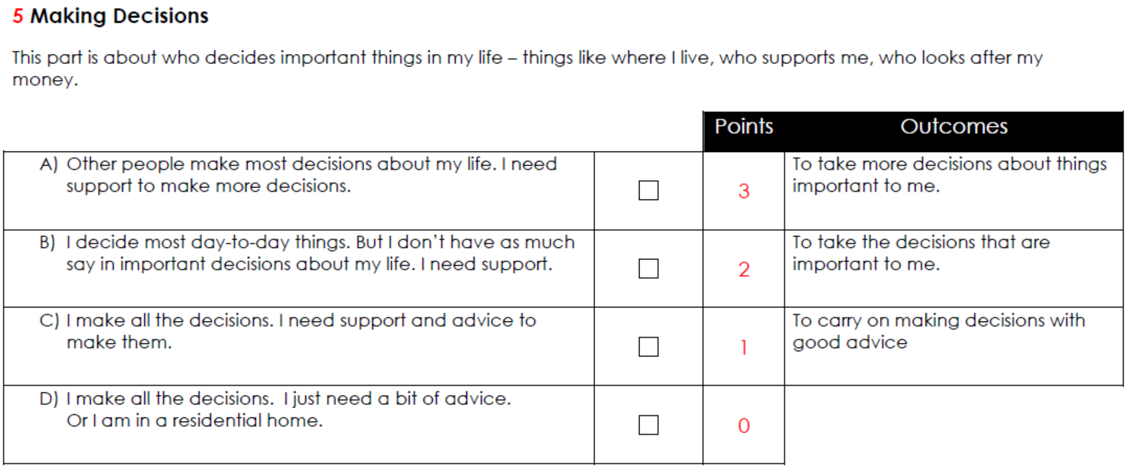
Thank you for completing the Self-Assessment online which indicates you could be eligible to receive some services from Kent Adult Social Services. A list of suitable services is shown below.

Please indicate which services you would be interested in receiving or knowing more about. Please tick **ALL** services that you are interested in.

Service	Select
Respite Care/Short Break - Help provided so that the carer can take a break from their caring responsibilities.	☐
Carer's Support - This service could allow a carer to go out or have a longer break; or help could be provided when the person cared for needs a lot of looking after.	☐
Further Information - We can give further information and advice about organisations that may be of use or interest.	☐
Benefit Advice - We can give advice and guidance to ensure you are receiving all the benefits you are entitled to or you can telephone the Benefit Enquiry Line on: 0800 88 22 00	☐

As noted above, the majority of local authorities in England have developed variants of the generic In Control self-assessment questionnaire. In Control SAQs provide the basis for the RAS covering eight key domains: meeting personal care needs; relationships; community participation; work, leisure and learning; making decisions; staying safe from harm; complex needs and risks; family carer.

The format is relatively straightforward with multiple choice type questions for each domain. The following extract is from the "Making Decisions" section of the In Control model SAQ (a copy of the full SAQ is attached as Appendix 1). (http://217.154.230.218/NR/rdonlyres/D7EB7F27-65FE-4A80-98CC-8634AF604A08/0/SS_HSelfAssessmentQuestionnaireSAQ.pdf)



5 Making Decisions

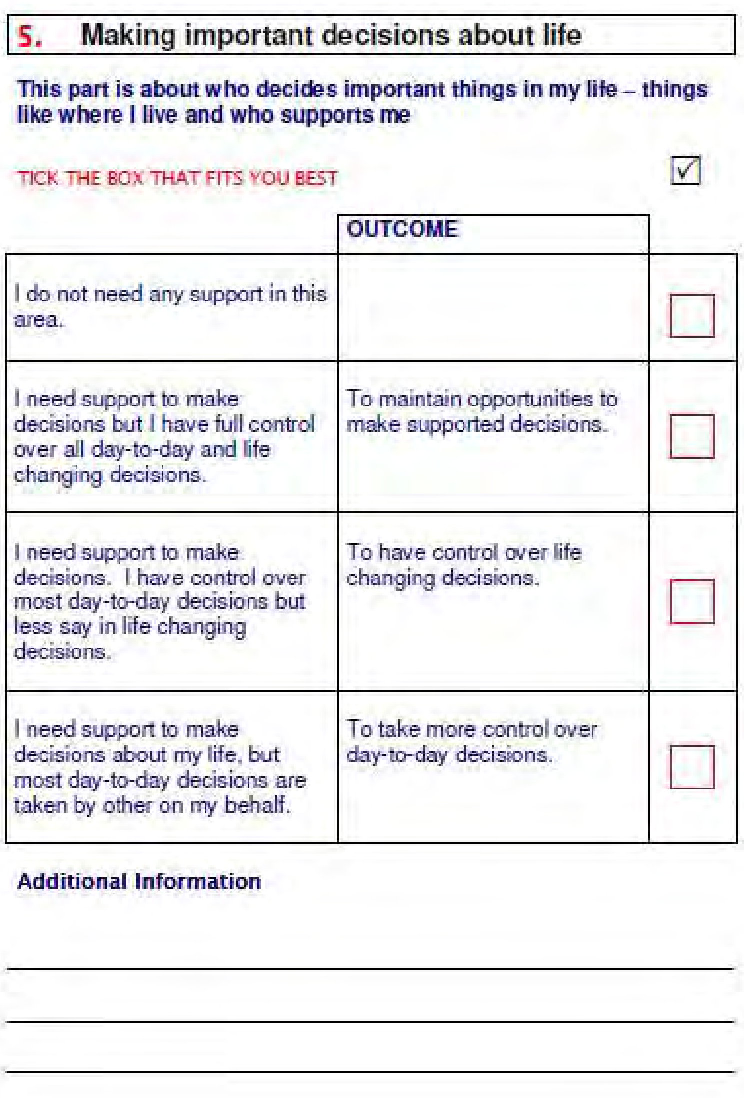
This part is about who decides important things in my life – things like where I live, who supports me, who looks after my money.

		Points	Outcomes
A) Other people make most decisions about my life. I need support to make more decisions.	☐	3	To take more decisions about things important to me.
B) I decide most day-to-day things. But I don't have as much say in important decisions about my life. I need support.	☐	2	To take the decisions that are important to me.
C) I make all the decisions. I need support and advice to make them.	☐	1	To carry on making decisions with good advice
D) I make all the decisions. I just need a bit of advice. Or I am in a residential home.	☐	0	

The version being used by Hartlepool Borough Council to help them allocate personal budgets is - considered to be "one of the best and most used self-assessment questionnaires in the country" -

(In Control website; John Waters, personal communication). The Hartlepool SAQ is a more extensive (18 page) document that builds on the In Control model SAQ. It is the means by which people begin to define and plot out a profile of their needs and begin to think in a systematic way about what it is that they want from life and how they might take control (Tyson, 2010).

The similarity to the original In Control model SAQ can be seen in the first extract below. The second and third extracts illustrate two of a number of additional questions which have been added to the Hartlepool SAQ, including sections covering: Eligibility Criteria, Current Support, Income and Accommodation. A copy of the full questionnaire is attached as Appendix 2. (www.in-control.org.uk/DocumentDownload.axd?documentresourceid=756)



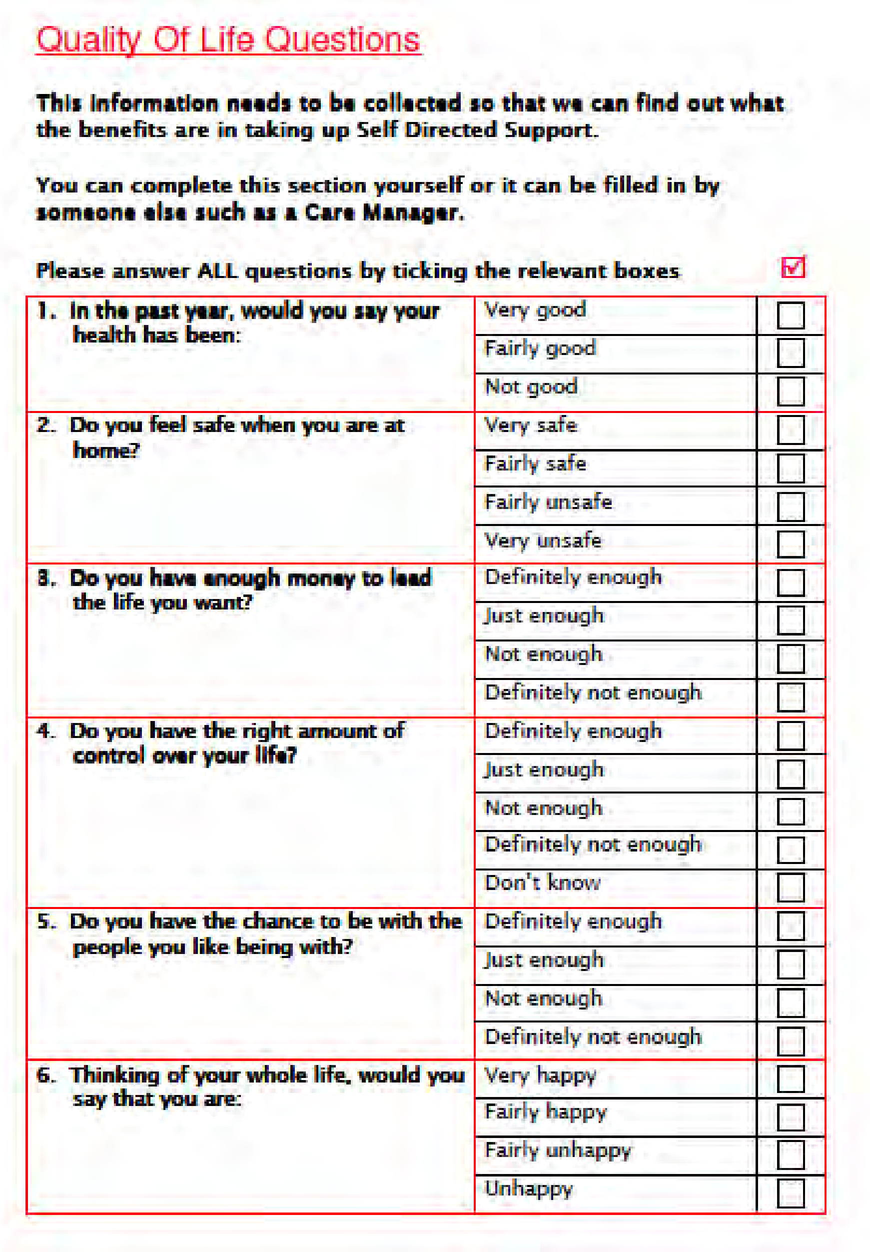
5. Making important decisions about life

This part is about who decides important things in my life – things like where I live and who supports me

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I do not need any support in this area.		☐
I need support to make decisions but I have full control over all day-to-day and life changing decisions.	To maintain opportunities to make supported decisions.	☐
I need support to make decisions. I have control over most day-to-day decisions but less say in life changing decisions.	To have control over life changing decisions.	☐
I need support to make decisions about my life, but most day-to-day decisions are taken by other on my behalf.	To take more control over day-to-day decisions.	☐

Additional Information



Quality Of Life Questions

This information needs to be collected so that we can find out what the benefits are in taking up Self Directed Support.

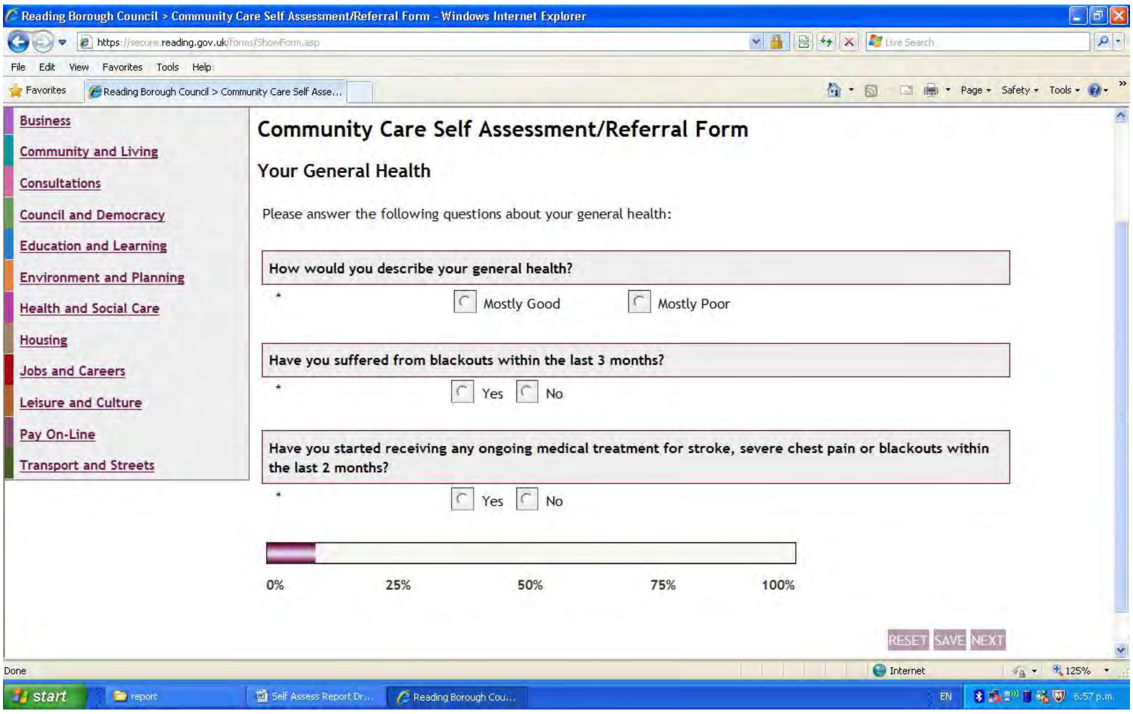
You can complete this section yourself or it can be filled in by someone else such as a Care Manager.

Please answer ALL questions by ticking the relevant boxes ☑

1. In the past year, would you say your health has been:	Very good	☐
	Fairly good	☐
	Not good	☐
2. Do you feel safe when you are at home?	Very safe	☐
	Fairly safe	☐
	Fairly unsafe	☐
	Very unsafe	☐
3. Do you have enough money to lead the life you want?	Definitely enough	☐
	Just enough	☐
	Not enough	☐
	Definitely not enough	☐
4. Do you have the right amount of control over your life?	Definitely enough	☐
	Just enough	☐
	Not enough	☐
	Definitely not enough	☐
	Don't know	☐
5. Do you have the chance to be with the people you like being with?	Definitely enough	☐
	Just enough	☐
	Not enough	☐
	Definitely not enough	☐
6. Thinking of your whole life, would you say that you are:	Very happy	☐
	Fairly happy	☐
	Fairly unhappy	☐
	Unhappy	☐

The Reading Borough Council online Self-Assessment/Self-Referral Form is for disabled adults and older people. It is not available in hard copy. https://secure.reading.gov.uk/forms/ShowForm.asp?fm_fid=324

Individuals are given the choice to either apply for a full assessment directly without going through the self-assessment process, or "follow the self-assessment process to see instantly if you (or someone you are concerned about) could be eligible for help from Community Care Services and then apply online if you want to." As the following extracts illustrate, this is a relatively simple form which asks a series of basic questions about an individual's health and abilities. The assessment is relatively comprehensive covering a number of key domains. http://www.reading.gov.uk/healthandsocialcare/communitycareservices/learningdisability/General.asp?id=SX9452-A7814FA2



Community Care Self Assessment/Referral Form

Your General Health

Please answer the following questions about your general health:

How would you describe your general health?

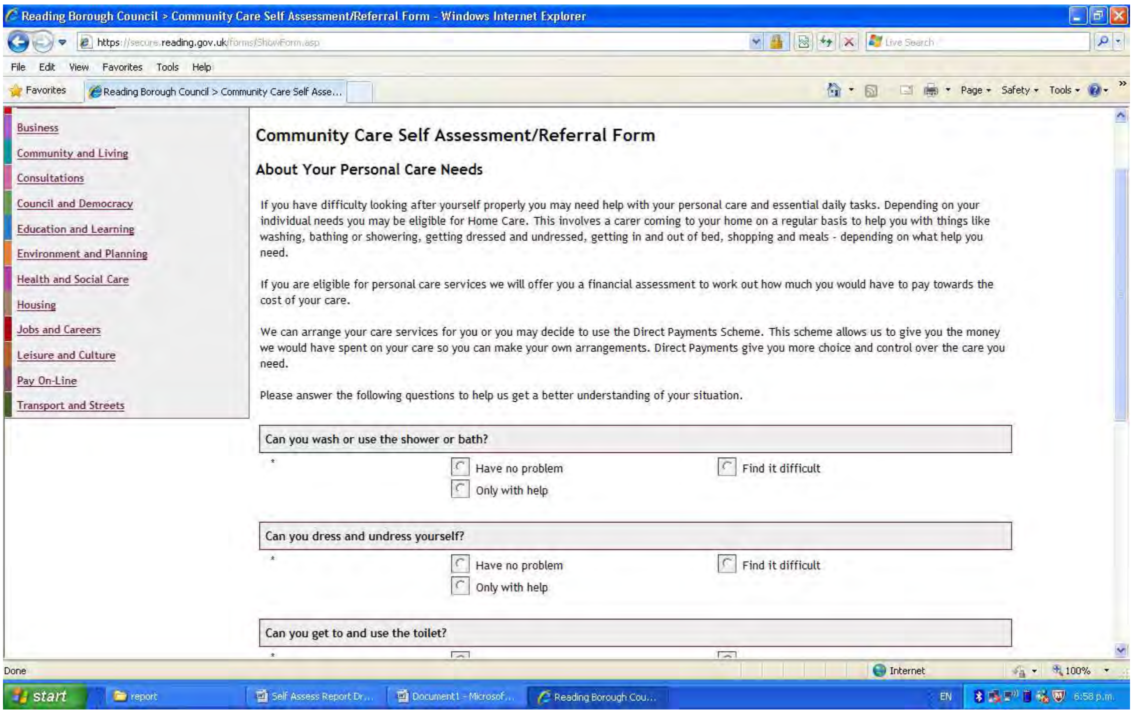
* ○ Mostly Good ○ Mostly Poor

Have you suffered from blackouts within the last 3 months?

* ○ Yes ○ No

Have you started receiving any ongoing medical treatment for stroke, severe chest pain or blackouts within the last 2 months?

* ○ Yes ○ No



Community Care Self Assessment/Referral Form

About Your Personal Care Needs

If you have difficulty looking after yourself properly you may need help with your personal care and essential daily tasks. Depending on your individual needs you may be eligible for Home Care. This involves a carer coming to your home on a regular basis to help you with things like washing, bathing or showering, getting dressed and undressed, getting in and out of bed, shopping and meals - depending on what help you need.

If you are eligible for personal care services we will offer you a financial assessment to work out how much you would have to pay towards the cost of your care.

We can arrange your care services for you or you may decide to use the Direct Payments Scheme. This scheme allows us to give you the money we would have spent on your care so you can make your own arrangements. Direct Payments give you more choice and control over the care you need.

Please answer the following questions to help us get a better understanding of your situation.

Can you wash or use the shower or bath?

* ○ Have no problem ○ Find it difficult ○ Only with help

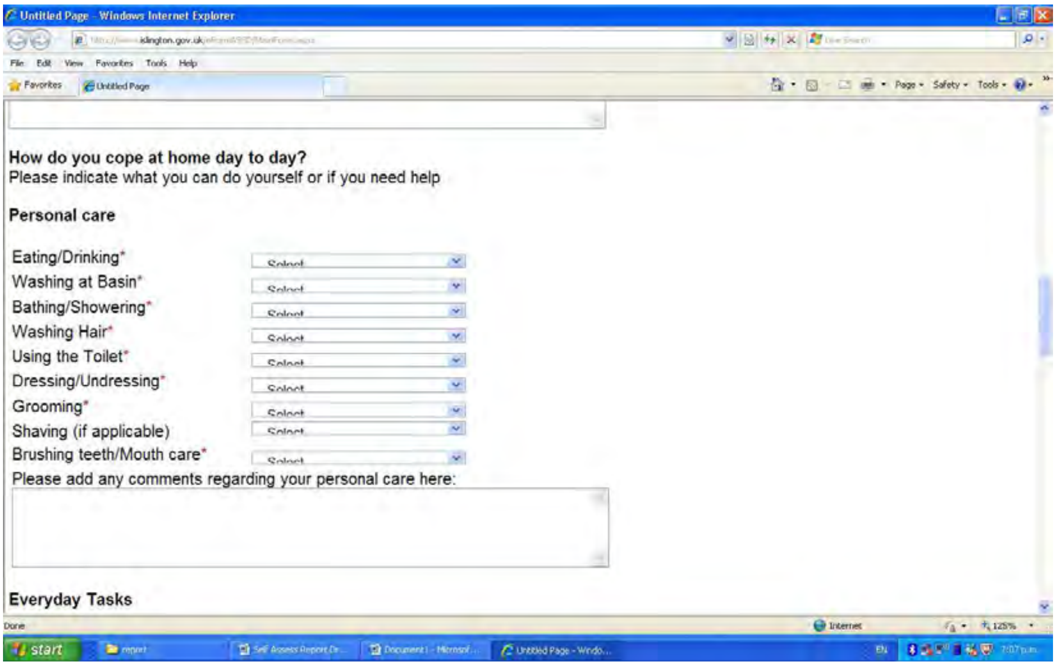
Can you dress and undress yourself?

* ○ Have no problem ○ Find it difficult ○ Only with help

Can you get to and use the toilet?

Similarly, Islington Council provides adults who are finding it difficult to manage every day activities with the option of initiating a needs assessment process online. http://www.islington.gov.uk/eFormASSD/MainForm.aspx. This is also a relatively straightforward form that progresses through a series of questions to which respondents select one of five responses to indicate their current circumstances:

- ✓ I cannot do this
- ✓ I can do this on my own
- ✓ I need help with this
- ✓ A carer (friend/relative) helps me with this
- ✓ I already have help from the Social Services with this



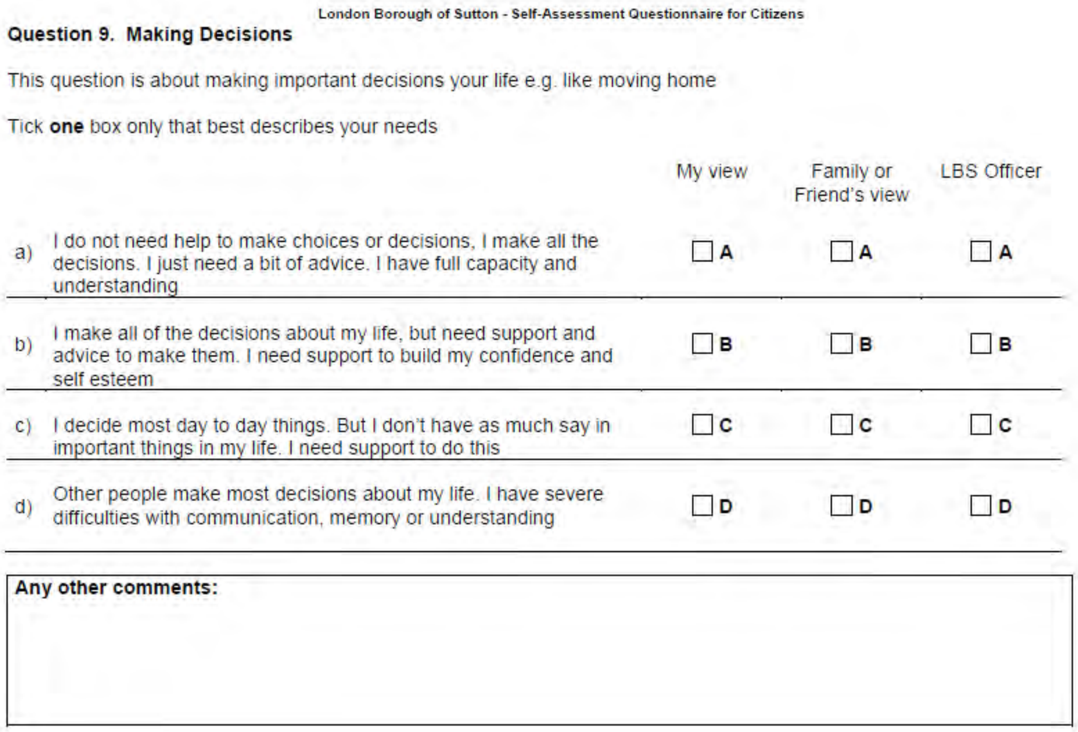
How do you cope at home day to day?
Please indicate what you can do yourself or if you need help

Personal care

Eating/Drinking* Select
Washing at Basin* Select
Bathing/Showering* Select
Washing Hair* Select
Using the Toilet* Select
Dressing/Undressing* Select
Grooming* Select
Shaving (if applicable) Select
Brushing teeth/Mouth care* Select
Please add any comments regarding your personal care here:

Everyday Tasks

The London Borough of Sutton SAQ is also used to initiate the assessment process and is followed up by phone contact and/or a visit. This SAQ is typical of many others using the multiple choice style format. The questionnaire asks the person to select the answer to each question that best describes their circumstances and has a section on each page for them to add more comments if they wish. Where it differs from many other forms, is that it provides an opportunity for an unpaid carer (family or friend) to give a response to each question and has a third space is for a final score “agreed” between the parties, including the professional assessor. This variation from the In Control model SAQ can be seen in the following extract, also from the “Making Decisions” domain.
https://spocc.sutton.gov.uk/LBSPORTAL/Downloads/Sutton%20Supported%20Self%20Assessment%20Questionnaire.PDF



London Borough of Sutton - Self-Assessment Questionnaire for Citizens

Question 9. Making Decisions

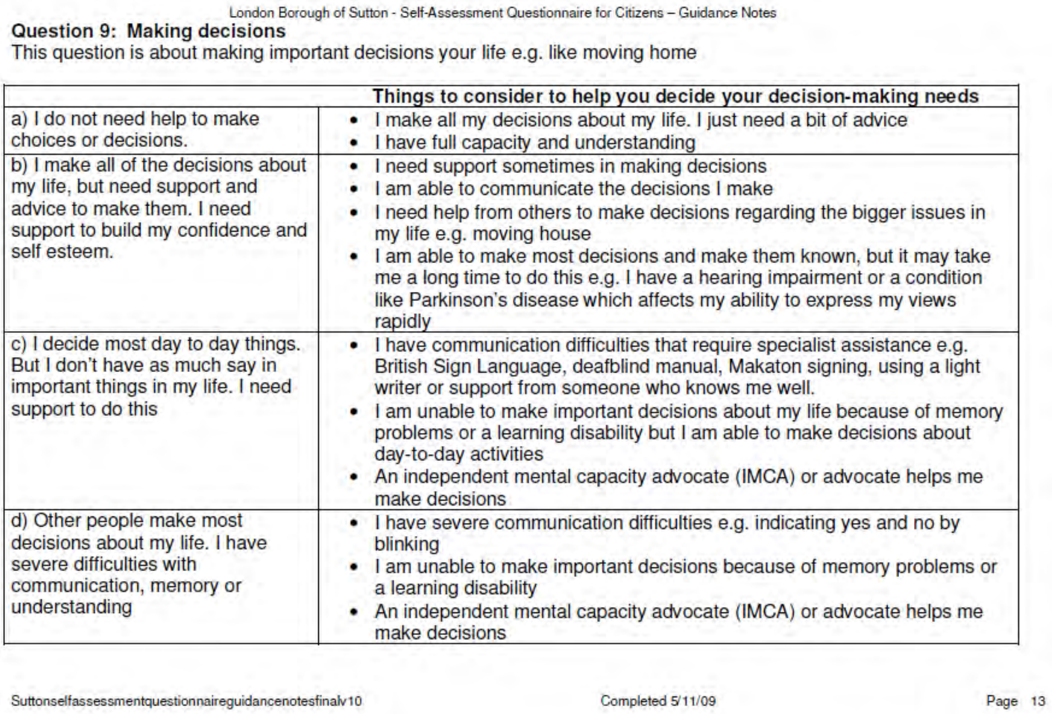
This question is about making important decisions your life e.g. like moving home

Tick **one** box only that best describes your needs

		My view	Family or Friend's view	LBS Officer
a)	I do not need help to make choices or decisions, I make all the decisions. I just need a bit of advice. I have full capacity and understanding	☐ **A**	☐ **A**	☐ **A**
b)	I make all of the decisions about my life, but need support and advice to make them. I need support to build my confidence and self esteem	☐ **B**	☐ **B**	☐ **B**
c)	I decide most day to day things. But I don't have as much say in important things in my life. I need support to do this	☐ **C**	☐ **C**	☐ **C**
d)	Other people make most decisions about my life. I have severe difficulties with communication, memory or understanding	☐ **D**	☐ **D**	☐ **D**

Any other comments:

The Sutton SAQ has a separate, comprehensive guidance document that is sent with the DSAQ explaining what each question is about. The section corresponding to the "Making Decisions" domain is presented below.
https://spocc.sutton.gov.uk/LBSPORTAL/Downloads/Self_assessment_questionnaire_guidance_notes.pdf



London Borough of Sutton - Self-Assessment Questionnaire for Citizens – Guidance Notes

Question 9: Making decisions

This question is about making important decisions your life e.g. like moving home

	Things to consider to help you decide your decision-making needs
a) I do not need help to make choices or decisions.	• I make all my decisions about my life. I just need a bit of advice • I have full capacity and understanding
b) I make all of the decisions about my life, but need support and advice to make them. I need support to build my confidence and self esteem.	• I need support sometimes in making decisions • I am able to communicate the decisions I make • I need help from others to make decisions regarding the bigger issues in my life e.g. moving house • I am able to make most decisions and make them known, but it may take me a long time to do this e.g. I have a hearing impairment or a condition like Parkinson's disease which affects my ability to express my views rapidly
c) I decide most day to day things. But I don't have as much say in important things in my life. I need support to do this	• I have communication difficulties that require specialist assistance e.g. British Sign Language, deafblind manual, Makaton signing, using a light writer or support from someone who knows me well. • I am unable to make important decisions about my life because of memory problems or a learning disability but I am able to make decisions about day-to-day activities • An independent mental capacity advocate (IMCA) or advocate helps me make decisions
d) Other people make most decisions about my life. I have severe difficulties with communication, memory or understanding	• I have severe communication difficulties e.g. indicating yes and no by blinking • I am unable to make important decisions because of memory problems or a learning disability • An independent mental capacity advocate (IMCA) or advocate helps me make decisions

Suttonselfassessmentquestionnaireguidancenotesfinalv10 Completed 5/11/09 Page 13

What is the user experience of self-assessment?

Clarkson et al. (2010) note that whilst arguments have been put forward as to the broad benefits to users of a more participatory model of assessment, particularly self-determination and self control, data on these aspects are difficult to collect. Consequently the literature concerning the measurement of user satisfaction with assessment is sparse, and particularly so for self-assessment in social care and life skills (Challis et al., 2008c; Griffiths et al., 2005). A review of the literature led Challis et al. (2009) to conclude that:

> The measurement of user satisfaction poses some rather contradictory challenges: it is methodologically straightforward and very easily implemented, but its tools nevertheless require cautious interpretation; it is widely propagated as desirable and therefore has become an omnipresent feature of service delivery, yet it is also hotly debated and often derided for its naivety (Challis et al., 2009, p.5).

These difficulties not withstanding, there are some lessons to be gleaned from the limited literature. In two reviews which focused on people's experiences of self-assessment in a variety of settings including social care, people considered self-assessment acceptable when they had direct support from a health professional (Griffiths et al., 2005) and when they were assured of its value and if they could seek additional professional help (Harris et al., 2006).

In a study of early IB users, Rabiee and colleagues (2008) reported that most interviewees found the self-assessment forms to be user-centred. Previous experiences of assessments, in which professionals decided what they needed, were reported to focus on what they could not do; but IB self-assessment and support planning were felt to be more about what they could and wanted to do. The processes were also felt to be holistic and encouraged people to think creatively about what they wanted to achieve.

Although some interviewees found the IB self-assessment form simpler than other self-assessments, several reported difficulties in completing it. These included questions that were difficult to understand, concepts that were subjective and open to interpretation and questions to which more than one answer applied. Some interviewees were also very concerned that giving wrong answers could have implications for the level of their IB (Rabiee et al., 2008).

The most comprehensive user experience survey was conducted in nine of the self-assessment pilot sites as part of the PSSRU study (Challis et al., 2009). It included more than 1,800, people accessing occupational therapy and preventive, assessment and care management services. The key findings of the study are summarised below:

- The majority of self and traditional assessment recipients found their assessment easy to complete and expressed a high degree of satisfaction with their experience
- Whilst there was considerable variation between pilots in the collection and sharing of information, there was no suggestion that either self or traditional assessments are better at this per se
- Users of online self-assessment found their assessment more difficult and less satisfying than did respondents participating in other forms of self or traditional assessment. All

other factors being equal, those completing on-line assessments were predicted to be six times more likely to find the assessment difficult and five times more likely to be dissatisfied.

- Socio-demographic and contextual variables predicted little of the variation in users' satisfaction, however
    - the completion of an on-line self-assessment was the strongest predictor of dissatisfaction or difficulty with self-assessment. Challis et al. (2009) suggest a possible explanation for this finding may be that the tools trialled were suboptimal for the service users they were tested on.
    - Asian service users, people with concerns about their memories and/or individuals who rated their health in the lower three categories also found it more difficult to self-assess
    - males and/or people with low mood were less likely to be satisfied with their assessment (self or traditional).

The authors conclude that the main lesson to be learnt from these findings is that:

> Self-assessment, while undoubtedly widely applicable, may ultimately not be for everyone. In their wish to drive forward the personalisation agenda, the policymaker must still leave some room for selectivity. Some user groups are likely to have legitimate reasons for needing extra help during the assessment process, or for having tools tailored to their needs, or indeed for being exempted from self-assessment. Insisting in such cases on unassisted forms of self-assessment would turn the very logic of the personalisation agenda on its head, emasculating rather than empowering service users in the process (Challis et al., 2009, p. 16).

Is self-assessment for everyone?

No single form of self-assessment is suitable for all service users or types of need. Some service users and carers may prefer an autonomous self-assessment, others peer-supported self-assessment while still others may seek professionally supported self-assessment or assessment led by a professional (Whittington, 2007).

Central to the use of self-assessment is the question "Does this person have the capacity to do some or all of this?"(Brewis, 2007). As Henwood & Hudson (2009) point out, the true test of the "personalisation" model is whether it

> Can work for people whose support needs are straightforward and stable, but whether it can also do so for people with complex, unstable, unpredictable needs, and where their capacity to indicate preferences may be limited (p.7).

Challis and colleagues (2008b) doubt the utility of self-assessment in groups with high levels of cognitive or affective disorder and suggest that existing assessment processes will continue to be required for frail service users. Findings from their study show that those who avail themselves of the opportunity to self-assess are atypical of those who hitherto have comprised social service user groups: they are healthier.

> A profile emerges of users for whom self-assessment may not be viable: people with cognitive impairment and generally poor health. It is also noteworthy that

> people with low mood were less satisfied with assessment processes whether they be self initiated or a more traditional approach. Poor health was associated with greater difficulty self-assessing and this was compounded if the assessment was electronic (Challis et al., 2008b, p.19).

A further concern is that people who self-assess may under-report their needs because of their fear of seeming demanding, low expectations or communication problems (Challis et al., 2008c). Challis and colleagues more cautiously (single site and single group data) warn that the difficulties of completing online self-assessment are exacerbated for members of black and minority ethnic groups. This suggests that online assessment has the potential to reduce access to service provision for traditionally hard to reach groups (Challis et al., 2008b).

People with fluctuating conditions have reported problems with both self-assessment and planning their support arrangements, because they found it difficult to predict the level of support they would need at any given time. As their condition changed, sometimes quite unexpectedly, so their support needs could change significantly too (Rabiee et al., 2008)

Carers of people with learning difficulties have argued that it was essential to have an advocate involved in assessment and support planning, to explain the self-assessment form; ensure that the individual's views were correctly represented; and challenge users' low expectations. This reflects findings that people with learning difficulties may have difficulty imagining alternative arrangements beyond their current situations. Independent advocates therefore appear essential to ensure meaningful and equal participation in assessment and support planning by people with restricted cognitive abilities (Rabiee et al., 2008).

Similarly, Foster and colleagues (2006) argue that, given self-assessment may be problematic for some groups of people with disabilities unless they also have access to high-quality, well-funded, independent advocacy services, it is essential to understand the conduct of assessments, who they are carried out by and the organisational, financial and managerial frameworks that shape the environments within which assessments are conducted.

Henwood and Hudson (2009) found that the major challenges to the operation of RAS were identified in accommodating high cost cases associated with complex needs; problems arising from cost ceilings on support for older people relative to other care groups; and uncertainty over how best to reflect the contribution of carers.

> Some people can just fill in the SAQ and we can add up the points, but when you get into the complex packages it's going to take a long time. You really have to get to know the person (Senior manager) (Henwood & Hudson, 2009, p. 66).

Form their evaluation of self-assessment pilots, Challis and colleagues (2008b) conclude that whilst the standardisation of service receipt consequent on self-assessment may be appropriate for some is not appropriate for all. Their study indicates that for vulnerable adults a personal assessment is the most appropriate means of assessing need.

> In terms of the delivery of social care the potential role of self-assessment is unclear. Whilst the evaluation does suggest a role, albeit limited, for self-

> assessment in the newly emergent configuration of care services it is not yet possible to clearly delineate this (Challis et al., 2008b, p.21).

The experience of carers

The IBSEN study concluded that there was a danger that carers' needs for support could be overlooked in the (self-) assessment for service users (Glendinning et al., 2009). With the exception of the one IB pilot site that had developed a separate carer RAS, sites had adopted different approaches to the treatment of carers' needs within the main service user (self-) assessment process and RAS (Glendinning et al., 2009).

A handful of sites had included a set of questions in the user's self-assessment aimed at determining what support carers provided; whether or not they were willing and able to continue providing that level of support; and if they were in need of support themselves. Fewer still had included questions in the main service user self-assessment form that specifically addressed carers' wishes in relation to employment, training/education and leisure activities, as legally required (Glendinning et al., 2009).

There were also reported differences between sites in the approaches to linking service user (self-) assessments for IBs and carers' assessments. Carer lead officers raised a range of concerns about IB service user assessments:

- Self-assessment forms not including 'trigger points' to prompt service users and/or social services practitioners to think about carers' needs. This risked the latter being overlooked, and/or, in the words of one interviewee, carers' support needs somehow 'popping out of the resource allocation machine'
- Carers' support being treated as an additional service for the service user, rather than services aimed specifically at the carer
- Not enough emphasis in the IB process to the 1990 NHS and Community Care Act and Fair Access to Care criteria, with the risk that councils might begin providing support for carers who, strictly speaking, did not meet local eligibility criteria, with subsequent large financial implications for the council
- Carers' needs and rights to help in relation to education, training, leisure and work being much more difficult to address within the service user RAS compared with carer breaks.

(Glendinning et al., 2009, p.30).

To address these concerns, a number of carers' lead officers considered there was a need to develop a separate RAS for carers. A key concern was to ensure that the impact of care-giving on a carer, and carers' commitments and aspirations relating to employment or training, for example, were made far more explicit than they were within a carer section of the service user RAS. In 2009, some pilot sites had already made a start on this, with carers' lead officers helping to develop self-assessment forms for carers (Glendinning et al., 2009).

As far as the processes of undertaking carers' assessments were concerned, the interviews with carers' leads suggested that the introduction of IBs had prompted some changes. These included: triggering a self-assessment process for carers, in addition to the standard face-to-face carer's assessment; and increased attention to the details of carers' roles within the service user's support plan. It was also suggested that there was potential for greater breadth in capturing carers' care-giving activities and consequent needs for support, but to date there was no evidence that this change had actually happened (Glendinning et al., 2009).

In a recent paper, Clements and colleagues (2009) consider progress in implementing IBs with particular reference to their relevance for carers. They report considerable variability in the approach by Councils in addressing carers' needs and provide examples of Local Authority Self-assessment and Supported Self-assessment Forms with significant apparent defects:

- One form describes what the social worker / disabled person consider to be the amount of 'informal care' that is provided - but does not have a column for the carer to give his or her view of this
- Although carers have a right to a separate 'private' assessment, this is in some cases negated by the fact that his or her views have to be set out on the same form as for the service user
- One form left no scope for saying that the carer simply does not choose to care
- Several councils' forms fail to identify whether there are children or young people under the age of 18 (required by FACS and guidance for the Carers Acts). It will be difficult to identify young carers if this question is not asked
- Some councils appear to be asking carers to self-assess the level of carers needs in isolation from a carers assessment
- Many councils are developing a carers RAS but in some cases this appears to be in lieu of the carers assessment influencing the main RAS (a requirement arising from the Carers Recognition and Services Act 1995).

(Clements et al., 2009, p. 15)

However, they also provide examples of where councils are endeavouring to embed carers' rights within new processes and this has included:

- Eligibility decisions (to access SDS) address risk to carers as well as people who use services
- Carers Assessments being embedded so that carers needs taken into account as part of the main assessment and not seen as an optional addition
- No automatic reduction being made to the resource allocation for the service user as a result of the carer being present
- Carers are specifically asked if they are able and willing to continue to provide the level of care they currently deliver
- The resource allocation is broken down and, among other things indicates how much should be deployed to reduce the carers input if this was indicated as a need in the assessment
- Carers' needs that are over and above those to directly support their caring role can be met through resources outside the service users RAS and a carers RAS designed to assist here
- The needs of young carers identified as part of the core process.

(Clements et al., 2009, p. 15)

Clements and colleagues (2009) argue that local authorities should involve carers in the development and evaluation of new systems for allocating individual budgets and explore whether the legal requirements described above are being effectively delivered and experienced by carers as positive outcomes. Furthermore, that there is a need for a clear Department of Health statement that personalisation procedure must address these vital (and legally obligatory) questions, not least:

- \- For carers to be asked directly whether or not they are willing to provide care (or the same level of care) regardless of the whether the current level of caring is onerous
- \- For carers to be told that the expectation is that they will have a carers assessment in private – ie that the information they provide may be given in confidence
- \- For carers to be asked about their wishes in relation to employment, training, education and leisure opportunities and signposting (at the very least) provided to support them in this respect
- \- To identify whether there are children or young people in the household and if so do they have caring responsibilities.

(Clements et al., 2009, p. 6)

What are the outcomes and effectiveness of self-assessment?

Given the use of self-assessment in social care settings is relatively recent, it is not surprising that this review has found very little research evidence about the effectiveness of self-assessment. This is consistent with previous reviews reporting a dearth of material and which have shown that where studies have examined the reliably of self-assessment in determining health need, results have been equivocal (Challis et al. 2008c; Griffith's et al., 2005).

As Challis et al. (2008c) note, unless self-assessment leads to different actions on behalf of the individual it would seem unlikely to lead to different outcomes from professional assessments, however professional interpretation and actions remains the norm. Indeed, they argue, this is one of the issues that self-directed models of support aim to address (Duffy 2005) and there is some suggestion that when individuals make decisions about their support needs, they select different services from those traditionally supplied by professionals (Challis et al., 2008c).

With regard to the particular concern that services users who self-assess may request more support that has been previous provided (Hancock et al., 2003), most of the limited available evidence relates to equipment. The early evidence from the implementation of self-directed support programmes suggests that people do not make frivolous or excessive demands (Henwood & Hudson, 2007).

Overall, self-assessment appears to have the greatest utility when it complements existing processes rather than substituting them (Challis et al., 2008b). In this way, it can contribute to the assessment and care planning processes, thereby linking with the personalisation agenda since it facilitates the users' involvement in the assessment. In contrast, requiring the user to complete the assessment process alone could be conceived as disempowering.

> The findings from the evaluation indicate that self-assessment has greatest utility when there is a facilitator (mediator) and/or a 'professional' person (not necessarily professionally qualified) to translate the assessment into an appropriate response (Challis et al., 2008b, p.19).

Is self-assessment cost effective?

While the literature around costs and cost evaluation in health care is voluminous, in social care the material is less extensive (Challis et al., 2008c) and there are few empirical investigations of the costs and benefits of self-assessment (Clarkson et al., 2010).

Self-assessment has been seen as a potential way of saving resources, particularly around 'back office' functions such as administration and paperwork and of freeing up professional staff to concentrate on the assessment of more complex cases. However, although the approach is discussed freely in academic and policy debate, there are few empirical referents as to its costs and benefits (Clarkson et al., 2010). A notable exception to the lack of empirical evidence in this area is the PSSRU evaluation of the Self-assessment Pilot Projects that provides useful material for this review.

Whilst the 13 pilot projects included in the evaluation were all defined by their promotion of self-assessment, they differed in a number of ways. A number related to innovations in occupational therapy services, others contributed to assessments within care management, whilst a third group focused on preventative services. The projects also varied as to whether they were designed to deliver direct access, to screen for further professional involvement, to identify a range of needs or to contribute to service planning (Challis et al., 2008a)

Challis and colleagues (2008c) addressed the question: *What kind of efficiency savings are thought to be generated by implementing self-assessment procedures?* In doing so, they found it useful to make a distinction between 'back office' and 'front office' costs. Back office refers to costs associated with functions that support the delivery of frontline services in contrast to those associated with the delivery of the service itself. Back office functions may include, for example, finance, human resources, facilities management and communication. In the community care setting, back office costs could include administration costs associated with assessments, technology support and staff dealing with telephone enquiries. Front office costs are those costs directly associated with the professional task, such as time spent in face-to-face assessment (Challis et al., 2008c). The key findings of this study are summarised below:

- The range of costs introducing self-assessment across the pilot projects reflected the different ways of administering self-assessment processes. The range of capital and revenue expenditure across projects was large. For revenue costs (including the cost of the assessment itself and service costs), seven projects produced cost savings and five incurred additional expenditure. The greatest expenditure was in occupational therapy services, followed by projects located within assessment and care management arrangements and preventative services
- In terms of the self-assessment process itself, most of the projects brought about cost savings in terms of the time of professional staff. One project was cost neutral, through employing self-assessment with an already existing facility. Four projects incurred cost savings wholly, or in part, from the use of workers in the voluntary sector
- For five projects where comparative data were available, two operated a self-assessment approach whereby service costs were significantly lower than that arising as a consequence of traditional, professional assessment

- In a case study of self-assessment and care management costs were lower than traditional assessment for: the assessment itself, in terms of staff time, and some services usually commissioned. Although self-assessed cases were offered more advice as to a wider range of preventative services (in line with the aim of the project), which generated greater costs, total costs were lower for this group. This cost saving arose from the use of staff with a lower unit cost who also spent time on administrative duties and gathering information
- In terms of cost savings from 'back office' functions such as savings in administration and paperwork, 12 of the 13 projects generated 'front office' savings, in terms of what happens during the assessment process and who provides assessment
- For a selection of seven projects where relevant data were available, self-assessment was found to be definitely cost-effective for two. These two projects were located within assessment and care management arrangements and generated greater benefit at less cost. Two projects (within care management and occupational therapy services) were more effective in terms of enhanced satisfaction, but were also more costly. Three projects (two within occupational therapy services and one within preventative services) were less costly but less effective
    - There is, therefore, a trade-off in judging the cost-effectiveness of self-assessment in policy terms, between whether efficiency savings or enhancement of the user experience is the preferred aim.

(Challis et al., 2008c)

Clarkson and colleagues (2010) reported on a pilot project that attempted to link access to assessment for older people with lower-level needs to the provision of a range of preventative services, through a self-assessment approach developed by one local authority. The study, undertaken as part of the larger PSSRU pilot site evaluation, evaluated the costs and benefits of the project. Although self-assessed cases were offered more advice as to a wider range of preventative services, which generated greater costs, total costs were lower for this group. This cost saving arose from the use of staff (self-assessment facilitators) with a lower unit cost who also spent less time on administrative duties and gathering information associated with the self-assessment (Clarkson et al., 2010).

Overall, the findings of the study indicated resource savings in terms of both 'back office' costs, such as savings of time on paperwork and gathering information, and also 'front office' costs, in terms of what happens in the assessment and who provides it. These findings read in conjunction with the finding that satisfaction with self-assessment was comparable to a professional assessment, suggests that self-assessment may be a "cost-effective approach in seeking to target assessment resources on a group traditionally neglected by the usual social services response" (Clarkson et al., 2010, p. 15).

Qureshi (2006) refers to this issue as the "time-saving and low bureaucracy versus risk." She argues that if the purpose of self-assessment is to decide on eligibility for statutory services then the authority is responsible for the outcome of provision, even if it plays no part in the assessment. The risk that people might receive inadequate or dangerous provision, or miss out on a wider assessment, has to be balanced against the benefits of swifter provision and lower bureaucracy. This tension can be resolved, she maintains, through safeguards built into the scheme and careful consideration of what should be provided in this way, together with periodic checking of outcomes.

Professional roles and workforce implications

There is growing debate about the degree to which assessment might be user initiated, user-led and used directly as a basis for provision without professional involvement (Qureshi, 2006).

Rabiee and colleagues (2008) reported on the experiences and outcomes of early IB users. In three of the sites (two of which also had In Control schemes), interviewees' self-assessments had been completed and support plans devised with the help of friends, family, social workers, care managers or inclusion workers. Interviewees valued the involvement of other people and several people felt that without this support potential IB holders risked under-estimating their support needs because they wanted to minimise their impairment; did not think certain things were important; or, in the case of fluctuating conditions, did not want to acknowledge that their condition could sometimes get worse (Rabiee et al., 2008).

The fourth site had run a series of workshops about support planning, involving representatives from most of the organizations involved with IBs. The interviewees from this site reported that the workshops were very useful, and that they felt adequately supported. In contrast, many interviewees in the other sites said that they would have liked more help with assessment and support planning (Rabiee et al., 2008).

All interviewees emphasised the importance of professional support during the assessment and support planning processes. While they all valued the freedom to think 'outside the box', some had found this a difficult task; in the past, they had been told by the professionals what they could and could not have and now needed help to learn how to plan their own support. A few people highlighted the importance of one-to-one mentoring from people who had already been through the assessment and support planning processes and the opportunity of learning from these first-hand experiences (Rabiee et al., 2008)

These results were confirmed in the full IBSEN study, with many care co-ordinators reporting that self-assessment usually involved some additional input from family members, friends or other professionals, who were seen by many as providing essential support, for example where service users could not fully understand the range of potential options. The types of individuals or organisations to whom service users could turn for support differed between pilot sites and, to a lesser degree, between user groups within the same site, but generally included family members, friends, advocates, voluntary organisations, brokers, support planners, peers, user and carer groups/organisations, in addition to care co-ordinators. People with learning disabilities or with severe and enduring mental health needs, and older people were all specifically identified by IB lead officers as needing different kinds of support, which related to their social networks, overall mental health or level of understanding (Glendinning et al., 2008).

Henwood and Hudson (2007c) contend that self-assessment is a challenging concept, and supporting people in completing a self-assessment questionnaire (SAQ), at least in these early stages, requires considerable care management input. Confirming this view, the IBSEN study also found that in all 11 sites where some form of self-assessment had been introduced, IB lead officers reported that most of these assessments also involved an element of support or checking by care co-ordinators. In contrast, two sites had not established any self-assessment process and reported that the assessment process was care co-ordinator-led, but was a collaborative endeavour, in which service users and carers were fully involved (Glendinning et al., 2008). In some cases, both the user and the care manager are completing separate assessments and then comparing the outcomes (Henwood & Hudson, 2007a).

In the Henwood and Hudson (2009) study on personalisation and complex needs, self-assessment was widely viewed as a misleading term. In practice self-assessment entailed intensive support from care managers working together with people to identify their needs and aspirations. Where this worked well it was viewed by care managers as a superior outcome to that attained by conventional assessment; however, it was more demanding of staff time and skills than traditional professional assessment (Henwood & Hudson, 2009).

As Browning (2007) notes, some of this extra time is spent because authorities are being cautious and tending to run care management assessments in parallel with self-assessments. This practice may be relaxed as experience and confidence are gained, allowing more streamlined processes.

Some studies have shown that individuals report less, or different needs from staff or carers who know them, and such work has been used to support the case for a professional assessment that probes beneath the presenting problem to identify ‘actual’ need, particularly where people have impairment and/or lack of insight (Challis et al., 2008c).

An alternative argument is that different stakeholders have different perceptions of need and that self-assessment allows user’s views to take precedence (Richards, 2000). There may also be scope for family members to take over assessments completed without the presence of a third party (Griffiths et al., 2005).

It may be that a professional assessment is still appropriate when it clarifies the nature of problems, assists in developing responses to them and advises on likely alternatives (Clarkson et al., 2010). The central question, then, is for whom and under what circumstances particular types of assessment are likely to be beneficial? Clarkson and colleagues (2010) conclude that a self-assessment approach may be for those with ‘low-level’ needs but, as difficulties become more complex or, importantly, if they require statutory powers to be invoked, then a professional assessment becomes justified.

Workforce implications

Self-directed assessment clearly implies significant changes for those currently undertaking professional assessments (Henwood & Hudson, 2007a). The change to a system of personalisation and supporting people in assessing their own needs and making appropriate support plans could be very challenging for staff and may require them to think much more flexibly and laterally than they have been trained to do (Henwood & Hudson, 2007b). A senior manager in Hartlepool Council commented:

> The current care management model of support is being radically transformed into a model of Self-Directed Support that focuses on the personalisation of social

> care. In the traditional model, social workers are care mangers who assess, plan, monitor and review care packages for people. With the SDS model, people complete a self-assessment form, they are allocated a budget and they then draw up a support plan to meet their perceived needs. People may or may not choose to use social workers to assist this process (cited in Tyson, 2010, p. 21).

As others have noted, it remains to be seen what the consequences of these changes are for the workers who, arguably, have the most change to embrace (Browning, 2007; Huxley et al., 2006). Indeed, others suggest that the pace at which self-assessment can be introduced within social care is likely to depend, at least in part, on the willingness and enthusiasm of staff (Challis et al., 2008c; Henwood & Hudson, 2007b).

However, as Henwood and Hudson (2007b) found in their evaluation of self-directed support, front line staff and their managers were particularly critical to the prospects of SDS development, including self-assessment. They were able to characterise a continuum of conceptualisations and judgements about SDS ranging from outright support, through qualified support, to qualified opposition and actual hostility. While people support the underlying principles, there are often substantial reservations about the practicalities of implementation.

Similarly, Challis et al. (2008a) reported that while some staff were open to the planned changes associated with self-assessment, by and large the initial responses were those of suspicion, concern and resistance. They were anxious about loss of role and status and also the safety of vulnerable service users. All of the managers in the pilots saw the projects as an opportunity to challenge entrenched professional approaches which they regarded out-dated and at odds with the agendas of personalisation, independence and choice (Challis et al., 2008a).

Henwood and Hudson (2007b) identified a number of ideological obstacles to the paradigm of SDS, including

> - The ‘giving and doing’ tradition: whereby social workers do as much as they can for service users and secure them the most support possible (often running counter to the requirements of the FACs criteria)
> - The loss of collectivism: where there is an apparent tension between the emphasis on the individual rather than on collective objectives
> - The conflation of needs and wants: in all our authorities, but particularly in the one that has had least engagement with SDS, there is a view that personalisation addresses people’s extravagant wants rather than their needs
> - And the mistrust of service users: both explicitly and implicitly there is widespread mistrust of service users and suspicion that people will seek to get as much out of the system as they can, while the professional has a responsibility to protect inappropriate demands on public funds.
>
> (Henwood & Hudson, 2007b, p.ii)

The Commission for Social Care Inspection (CSCI) review highlighted some fundamental problems about how local systems respond to people seeking support and recommended that assessors, or those supporting self-assessments, should be skilled in understanding people with a range of needs so that specific groups of people are not marginalised (CSCI, 2008).

It is difficult to predict what effect the changes in social care will have on existing workforces. The current role of the care manager as assessor, rationer and prescriber of support services is challenged by the emphasis on ‘self-assessment’ and on the individual being able to have their own ‘personal’ or ‘individual’ budget and support package (Beresford, 2009). Renshaw (2008) argues that both self-assessment and self-directed support undermine traditional social work and that social workers need to begin to work alongside disabled people, rather than ‘for’ disabled people, in order to achieve substantial system change (Renshaw, 2008).

Browning (2007) notes that while some have speculated that there will be a reduced need for care managers in due course, pilot sites are yet to report any reduction in demand on care management time. He also reports that, while it might appear, at first sight, that care managers may no longer be needed, in reality authorities are finding that they are needed for a number of key tasks:

- Helping people to complete the questionnaires. While many people can do this for themselves, some may need a great deal of help. Frail older people in particular are reported to ask for a lot of help
- Ensuring that people have filled them in correctly, and not under or over-estimated their needs
- Helping people to identify the outcomes they wish to achieve
- Checking that these outcomes cover all the necessary issues – and in particular that any risks are identified and addressed satisfactorily. This is a particularly important aspect, if people are to be kept safe and well, as many people may not recognise some of the risks they face. By doing this, their local authority is also able to discharge its duty of care. This does not mean that risks are avoided, but that they are identified and managed
- Gathering intelligence to help commission new services to meet emerging needs;
- Providing social work support, with many people benefiting as significantly from the care, attention and support provided – the feeling that somebody is interested in them and cares - as from the resulting services.

(Browning, 2007, p.13).

Similarly, Griffiths and colleagues (2005) write that “even the most innovative self-assessments require appropriate action by professionals” and Qureshi (2006) remarks that “it is generally still for professionals to make the final decision about allocation of public resources.” However a tension implicit in the self-directed funding model has been identified, with several individual programme evaluations and larger reviews underlining the importance of separating the planning process from decisions about funding allocations. Requiring caseworkers to conduct assessments and assist with planning while they are also responsible for allocating budget amounts may create a conflict of interest that strains their relationships with clients (Chopin & Findlay, 2010).

As noted elsewhere, the workforce can no longer be described simply in terms of local authority or independent sector, but must also include family carers, volunteers, advocates and brokers (Hudson & Henwood, 2009). The self-assessment pilot projects provide some limited evidence of the widening role of the third sector. Representatives of voluntary organisations have acted as mediators in the self-assessment process within both assessment and care management and occupational therapy services. They have also been the purveyors of information about self-assessment (Challis et al., 2008).

It is well established that service users particularly value turning to people with shared experience for support and guidance. Service users' own user-controlled local organisations have pioneered models and roles to support self-assessment through providing advocacy, information and technical backup and there is evidence that services, run by such organisations, are particularly valued by service users and are effective (Beresford, 2009). By developing training and roles for people with experience as service users, two issues can be addressed: making self-directed support more accessible for all; and providing valuable skills training and job opportunities for service users (Beresford, 2009).

Issues and concerns

It is clear from the literature that for many professionals, self-assessment is a challenging concept - there are mixed views about how it might operate and about the perceived risks associated with its adoption presents. These concerns would seem to arise from lack of knowledge of the operational detail of how self-assessment works, a lack of experience with implementation and the challenge presented by the transfer of power from professional to service user.

The primary concerns about self-assessment reported in the literature (Browning, 2007; Glendinning et al., 2008; Henwood & Hudson, 2007b; 2009; Newman & Hughes, 2007), can be summarised as:

- Individuals will make frivolous or excessive demands
- People may underestimate the nature and complexity of their needs
- People -will assess their needs inappropriately and 'misuse' the resources they are allocated
- Self-assessment will become a 'token' activity
- Service users could lose important face to face contact
- Understanding how self-assessment fits with current processes and eligibility criteria
- Self-assessment will involve balancing an increased demand with a constrained budget.

Evaluating the implementation of self-directed support, Henwood and Hudson (2007b) found that the idea of self-assessment was the focus of considerable uncertainty and some anxiety. Whilst respondents may have been comfortable with the concept of 'putting the person at the centre', it was another matter to accept that this should mean self-assessment. Most were concerned about needs and wants becoming confused and were concerned about how to protect limited resources from potentially unlimited demand (Henwood & Hudson, 2007b).

It was also apparent that for some respondents the discomfort with self-assessment reflected a mistaken belief there would be a 'free for all' where people could demand – and receive – anything they wanted. Conversely, there are concerns that users engaging in self-assessment may under-assess their needs and that take-up will be uneven between user groups (Henwood & Hudson, 2007a; Glendinning et al., 2008; Newman & Hughes, 2007)

Some respondents in the Henwood and Hudson study (2007b) feared that service users could potentially lose important face to face contact and the benefits that arise from that. Some struggled to understand how self-assessment would be operationalised – what it would mean in practice. In addition, many people struggled to understand what self-assessment was all about and whether it would mean, for example, that FACs principles were abandoned and eligibility would cease to be relevant (Henwood & Hudson, 2007b).

Emerging evidence suggests that the reality is often less challenging than had been anticipated and people's demands are relatively modest. It is not the case that people – when given the opportunity to specify their own needs – all demand services that others might deem frivolous or excessive. Rather, people may define their needs differently to the standard services that have long been offered (Henwood & Hudson, 2007b).

Similarly, in the IBSEN study a number of the pilot sites had experienced people with mental health problems and older people in particular under-assessing their own needs , however, people with physical disabilities, sensory impairments or learning disabilities were more likely to over-assess their needs (Glendinning et al., 2008). These findings were attributed, in part, to older people having low expectations, and of people with mental health problems being in denial about their needs, or not perceiving their actions or behaviours to be anything unusual. Henwood and Hudson (2009) also reported that the risks of people underestimating their needs in the self-assessment process were widely recognised.

In contrast, several IB lead officers reported that care co-ordinators tended to over-assess people's needs; and that there was a culture of care co-ordinators trying to get the 'best deals' for the people they worked with, particularly perhaps for those who were the most difficult cases and/or were the most likely to complain. The RAS was considered by some to be much more objective as systems were in place for each decision to be justified and the path from assessment to allocation was expected to be more transparent. (Glendinning et al., 2008).

Implementation and sustainability

In Volume III of the self-assessment pilot evaluation study the authors considered the implementation and sustainability of innovation in public sector social care settings (Challis et al., 2008a). Overall the findings show that the implementation of innovation is a

> Complex matter comprising a variety of attributes concerning the innovation itself, its host organisation and its situational context, none of which are uniform to all but individually, even uniquely, combined (Challis et al., 2008a, p. 64).

The evaluation incorporated a wide ranging review of literature which highlighted key factors influencing these aspects of innovation. Although the authors concluded that there is no single recipe for successful implementation no 'road map for others to follow" (p 69) the findings hold useful lessons for other innovation implementation (Challis et al., 2008a). A summary of key findings from this report follows:

- ***Level of political mandate*** is an important attribute in relation to the sustainability of new initiatives

- ***Links with existing services*** - the more closely an innovation is related to existing services the more likely it is to be maintained long-term. Relevance to the wider agenda is no guarantee of sustainability, but it is a necessary foundation to achieving this
    - This was reflected in the pilot projects by such things as how funding was used, whether processes were embedded in existing administrative systems or additional to them, or by the day-to-day management of the projects
    - Making real/operational connections between the pilot work and other development in the department was also an important aspect of sustainability
- ***Partnerships*** – the involvement of more than one organisation increases the complexities of implementation
    - Misunderstandings can emerge from the lack of shared language and understanding between partners, especially when this involves partnerships between professional and voluntary agencies
    - Partnerships are particularly important in dealing with cultural and ethnic diversity
- ***Sufficient finance*** is important for the successful implementation of innovation, however the use made of funding may be more significant than the amount
    - Projects that had used funds to finance additional staff and/or for web tool licences were likely to require further funding to continue to operate beyond the pilot
    - The expense and effort to sustain projects was likely to be less for projects which operated alongside existing systems compared to those which were outside mainstream practice or only operated in part of the authority
- ***Scale and complexity of change*** –it appears that it may be easier for new initiatives to be accepted into mainstream practice if they reflect an incremental rather than model shift in practice. The more complex the new process the more difficult it is to implement
- ***Clarity of purpose*** - .a clear understanding of the purpose of the innovation is important to its implementation. To be successfully implemented, an innovation must be seen to provide an effective response to the problems it was intended to deal with
- ***Adaptability*** - flexibility and the ability to adapt to unforeseen circumstances is more likely to lead to successful implementation in the long term
- ***Management and leadership*** – managers and 'change agents' can not produce change in a vacuum, however they do play an important role in stimulating and championing new systems
    - Visible and ongoing senior management support is important for sustainability
    - Change agents can come from within or outside an organisation, but must have credibility amongst those who are engaged in implementing innovation
    - The literature is equivocal about whether innovations are best implemented as 'top down' or' bottom up' initiatives
    - The top down diffusion of innovation from 'expert' to users is a centralised approach that utilizes the influence of those in positions of authority
    - 'Bottom up' approaches that encourage the participation and engagement of those affected by the change are believed to lead to more successful innovation

- ***Use of information technology*** is clearly central to the future delivery of social care, including assessment and service delivery. The ability to obtain appropriate IT systems and support is an important factor in the promotion of implementation
    - In most of the pilot sites, the role of technology was in the form of access only with forms accessed via websites and printed for manual completion. In others, online completion of SAQs was possible and in four sites the web tool was capable of determining service receipt
    - The take-up of web based assessment and/or an information service varied between projects, but was most successful where support was available
- ***Challenging the culture – changing staff perceptions*** - organisational culture is a force that can hold back change as the customs, practices, and support or resistance of staff can have a major impact on implementation. It is better if innovations are in tune with existing culture
    - The self-assessment projects were largely seen as challenging the prevailing culture and all faced challenges from staff resistant to the changes. Dealing with these issues took time and resources and slowed down the pace of innovation
    - Staff can be supported through a variety of means, but it is important to keep them informed of the changes and provide opportunities for them to voice their concerns
    - Training and involving staff directly in developing new processes can facilitate engagement in the project
    - A number of the pilot projects successfully utilised 'change champions' to lead the way in the change process
- ***Marketing and publicity*** are now accepted as having a role in public sector services as a means of learning about the public's experiences, perceptions and concerns about current services and to tailor future services to better meet the needs of service users
    - Mangers in the pilot sites were concerned that publicising new services might overload a system already under pressure and raise expectations that would not be met if the 'pilot' was not continued.

Others have also highlighted the need to promote a culture of self-assessment amongst its users and within self-assessment projects (Henwood & Hudson, 2007a; Qureshi, 2006) and a number of ways to achieve this have been suggested:

- Mechanisms should be in place to ensure that attention is given to the information from self-assessment, and that some action follows based on it
- The purpose of self-assessment should be clear
- People -should have choice about the stage at which they would like professional involvement, and/or assistance from advocates
- Work is needed on the development and testing of self-assessment materials, both the tools per se and their use in operational contexts.

(Qureshi, 2006)

Whilst it is clear from the findings above that a number of factors are important in the implementation and sustainability of innovation in social care, according to Challis and colleagues (2008a), their study holds a key message, above and beyond those which match the findings already present in the literature – that is how 'embedded' a project has become by the end of the pilot. The concept of an embedded service or process relates to:

> The position of the project manager; the use of funding and whether or not additional monies are required for its continuation; the ability of the project to use existing structures and resources; of being regarded as in tune with other practices and developments; and of having a broad strategic fit (Challis et al., 2008a, p. 65).

Whilst the means adopted to achieve 'embedded-ness' varied, the attributes which appeared to be significant included:

- The status of the pilot projects
- Their purpose in testing out ideas for adaptation to better fit user need
- The adoption of a marketing approach in respect to changes in the way services are delivered
- The ability of projects to demonstrate their success to provide leverage for political support; and
- Their capacity to act as catalysts for wider change.

The latter is particularly important in that it signifies the influence of innovations over and above their particular brief, irrespective of whether they were sustainable as entities in themselves. (Challis et al., 2008b).

Well experienced with self-assessment, John Waters from In Control recommends "keeping it simple." In a personal communication (2010), he offered these key summary lessons from the In control experience:

- Self-assessment is possible but it requires professionalism, to let go of power and control
- It threatens professional power and there is a cultural challenge to accept a system based on trusting disabled people. In UK 'assessment' is the only legal entitlement for a citizen and duty for the govt, in relation to social care, so without replacing these with better alternatives, i.e. right to certain outcomes, or a duty to act reasonable to ensure well-being there is a risk that a shift towards self-assessment erodes statutory protection
- Keep the whole thing simple so people can understand it and the assessment is viewed as fair by the person their family and the state
- Separate the measurement of level of need and social support (that informs allocation of money) from information on individual wishes preferences aspirations (that shape the support and the planning)
- Set the out come as part of the allocation decision, so choice and control over the use of the allocation rest with the individual, but is constrained by reasonable parameters.

Part two: Stock-take

Method

Telephone interviews were conducted with 18 NASC managers and/or senior executives from 16 NASC contracted agencies (or branches) nationwide.

The interviews followed a standard format using a brief interview schedule (Appendix 3) and were conducted by Dr MacDonald. A record of each interview was compiled and sent to the interviewees for verification and amendment where necessary. A full list of those who participated in the interviews is attached as Appendix 4.

Results

Use of self-assessment

Of the 16 agencies that provided information for the stock-take, only one reported using self-assessment, and two utilised modified processes which included elements of self-assessment. A number of others spoke about the occasional use of 'adapted or 'flexible' approaches to assessment that incorporated components or principles of self-assessment.

FOCUS (Wairarapa) created a telephone-based assessment tool that they use with those needing household management only. These are mostly older service users (over 65) DHB clients but also some low need service users who do not meet Ministry of Health requirements.

The FOCUS referral forms have a check box for "needs house work only" which, when ticked indicates that the client has determined that they need help. In response, the "self-assessment" occurs by telephone with FOCUS staff completing an electronic form to determine eligibility to service.

The tool was developed in-house about 3 years ago with involvement from consumers and providers. Implementation involved initial testing by the manager then training of a "super user" before being rolled out to remaining staff. The FOCUS manager reported some initial barriers with staff who "didn't believe that they could do it without seeing the consumer."

FOCUS report positive feedback from both consumers and providers. As a result of the initiative the waiting list has been reduced from 8 weeks to 1 week and "coordinators are triaging more rather than using a blanket approach."

In Northland, NorthAble do not formally have self-assessment in place but they have adapted the national assessment incorporating a "navigator" model of support in a broad outcome focused role. Navigators, purposefully matched to families, use a range of tools as they see appropriate in assessments and "empower the families to recognise what they need and to get back their resilience." NorthAble report that they have had very positive feedback about these roles in which families are empowered and feel that they learn to navigate for themselves. They are now looking at children's assessment.

LIFE Unlimited (Petone and Hamilton) have developed the following self-assessment process: a referral is received; once eligibility is determined the referral is received by the "Integrated assessment facilitator" (a new established role). The facilitator makes an initial telephone contact and explains "who we are, what we do, the process etc. Those with low need are offered four options for assessment, each with a slightly different format:

1. - Self-assessment using a mailed printed form
2. - Self-assessment using an emailed printable form
3. - Face-to-face in the home or office
4. - Via telephone

The self-assessment is a three-step process: the initial "front end" telephone conversation; completion of the self-assessment; a follow-up telephone conversation which provides an opportunity to clarify detail, probe for further information if required and explain what will happen next.

Handwritten assessments are entered electronically (unedited) with any additional information added below to ensure it is clear who the author of all the information is. The assessment is returned to the service user for their verification/amendment.

LIFE Unlimited started work on self-assessment in August 2009 and note that it has been a slow process to get to where they are now. In the first nine months of 2010, 30 people had used self-assessment (40% of those who were offered the option). These were mostly (70-80%) parents of children with disabilities such as ASD and ID. They deliberately started with people at the low end of need "because these are usually straight forward." The process and forms were developed in house through repeated testing and refinement, including client feedback. "Our self-assessments reflect New Zealand culture, disability culture, language and experience of being Kiwi."

LIFE Unlimited report that feedback from clients and others has been very positive and that no one has struggled with the form. The value, they see, is that self-assessment can happen at a time that suits the person and family, such as at the weekend when other family members can be present. They also report that what is also valuable is that other information can be added, such as a paediatrician's report which means "parents can talk about impact rather than medical/disability detail which is provided in the report."

The interviewee commented that there a sector myth that people can not do assessments, that they do not have the skills or ability. LIFE Unlimited report that this is not the case, rather that it "has been a revelation; some people do a great job." Their plans for the future include:

- \- Creation of a pack including essential information and some fun things (pen, jelly beans, coffee – a "survival kit") to make the experience less daunting.
- \- "Market" to support groups, such as IHC, MS so that they are knowledgeable about the self-assessment option.
- \- Investigate putting it on the website and look at Skype.
- \- Independent research to validate what we think we know and understand

- Consider moving this option to people with high and complex need -

Views of self-assessment:

A number of respondents said that they had not really thought about self-assessment until they received the request to participate in this stock-take, and that this has stimulated their interest, with some then searching for more information on the topic. Most were positive, if somewhat cautiously, about the future role of self-assessment in the New Zealand context.

There was a general consensus among the interviewees that self-assessment involves a person completing their own assessment (with or without support) and providing information from their perspective. The key difference for most was that whilst current assessments are face-to-face, self-assessment would be largely independent of professional input.

Most interviewees spoke about self-assessment as part of a self directed or self managed approach – empowering the client and giving them more choice and control:

> To empower a person to give information which they choose to give, including their strengths as well as disability, the aspects they are managing well and future goals

Seven of the interviewees referred to cost-effectiveness, of streamlining work allowing more time to be spent with those of higher need and/or providing a quicker, less invasive service.

The question, under what conditions, and for whom, is self-assessment most appropriate? was perhaps the most challenging for respondents. It raises the dilemma of not wishing to exclude anyone, but recognising that self-assessment depends on the ability of the person to complete it or to articulate their thoughts to someone assisting them to complete it.

Some (6) interviewees felt that all people should be offered the choice, even though some people may need more support/assistance than others. Several (7) thought that self-assessment would be inappropriate for people with high and complex needs, that it would be more appropriate for those able to engage in conversation, to advocate for themselves and to communicate their views.

> People with physical and sensory disabilities may be able to do it more easily than say, those with intellectual disability who may need more support – it depends on what they can do.
>
> It would need to be someone with very good understanding and able to articulate and communicate their views. It depends on the level of these. For example, it would not be appropriate for the intellectually disabled or those with dementia or otherwise cognitively impaired.

There was a general consensus that self-assessment would be appropriate for those with low need, such as those who only want a few hours of household management.

> There are current clients in the system with low service provision who have to have an assessment every 3 years. This is an unnecessary intrusion. Self-assessment would be good for them.

However, there was also concern expressed that people do not always know what they need, that they may think their need is low but through the facilitated assessment it is clear that they need more:

> They may only think they need a few hours of household management help but may actually need more.

When discussing the key domains for assessment, interviewees recognised that the self-assessment needs to furnish

> Enough information to cover off everything, to make sure you don't miss anything, to have enough information to determine resource allocation.

However there was a sense that the current approach was lacking, that self-assessment needed to use a strength-based rather than a 'deficit' approach and that more emphasis needs to be placed on families, networks and the opportunities that these have to provide for support.

> It needs a different emphasis – the current tool focuses on what they can't do, rather than on what they can do. It needs to be vision/goal oriented and look at the barriers and a plan to achieving the goals.

In addition to those already mentioned above, a number of other issues or concerns were expressed about self-assessment, including

- The challenge of tracking the economic impact of self-assessment
- The risk that self-assessment could create an even more convoluted process because of the need to go back for more information
- It requires a nation-wide approach with clear criteria such as with InterRAI where you could come up with a points allocation
- A self-assessment tool, whether or not it is facilitated, needs to be part of a complete process which incorporates a flexible range of communication vehicles through which assessment can occur
- How do we mitigate against risk for vulnerable people?
- We must be mindful that the assessment should be based around clients needs – not what the family wants
- Wants and expectations do not necessarily equate with need
- A risk with self-assessment is that it does not facilitate a holistic approach
- There is a risk that the group of service users who know what they want and can well articulate and communicate this, will be the ones to get the resources when others do not. The self-assessment process could end up going down the entitlement path with a risk of pre-conceived expectations/entitlement.

Part three: Recommendations and discussion

Design options for process, tools and implementation pathways

The following recommendations and discussion have been informed by international experience and evidence and practical knowledge of the New Zealand disability support services environment. However it should be noted that the use of self-assessment in social care settings is relatively recent, it is not widespread and there is limited documented evidence about the implementation, efficacy and outcomes of self-assessment, particularly as it pertains to DSS.

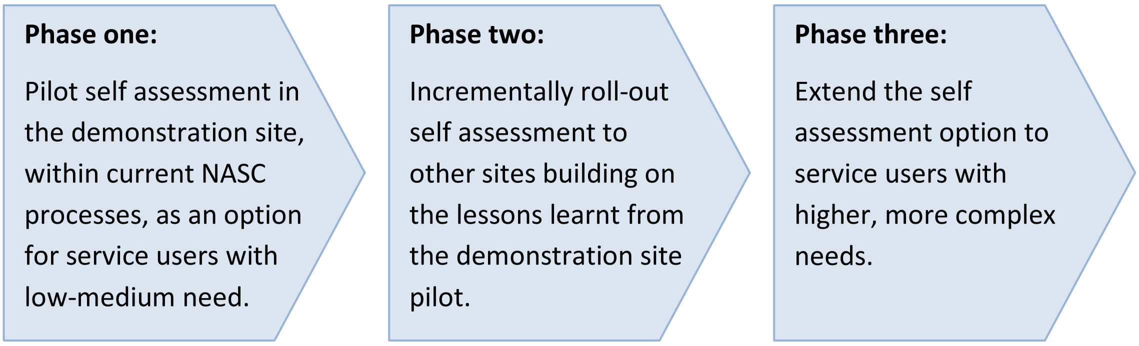
It must be noted that for the purposes of this review and report, self-assessment has be regarded largely as a separate or clearly identifiable entity. In reality self-assessment is one component of larger, complex processes and models of service delivery. In the In Control model, for example, self-assessment is an integral part of the RAS. Until there is a clear understanding of how the IF and RAS will work in New Zealand, it is not possible to make definitive recommendations about self-assessment in that context. These processes, should however, be developed concurrently.

It is also important to be clear that self-assessment is not about assuming any predetermined allocation of resources. However it does align with the recommendations in the DeLoittes report to allow service users to self prioritise their support needs (DeLoittes, 2010)

A particular challenge has been to develop recommendations with respect to self-assessment in relative isolation to the ongoing work related to the new model/framework to support disabled people. How the implementation of the model evolves in the demonstration site will undoubtedly impact on the development and implementation of self-assessment in New Zealand. At this point in time it is not possible to determine what impact that may be, but as the model evolves phases 2 and 3 in the following recommendation may be quite different than what is suggested here.

The following recommendation on overall approach is made on the basis of the findings of this review, local knowledge, and well accepted principles of change management:

Recommendation 1: that self-assessment for disability support services in New Zealand is introduced in a three-phase incremental approach, as outlined in figure 1.



Phase one:

Pilot self assessment in the demonstration site, within current NASC processes, as an option for service users with low-medium need.

Phase two:

Incrementally roll-out self assessment to other sites building on the lessons learnt from the demonstration site pilot.

Phase three:

Extend the self assessment option to service users with higher, more complex needs.

Figure 1: Recommended approach to implement self assessment in New Zealand

Through the three-phase incremental approach it will be possible to:

- Minimise risk by testing self assessment in the demonstration site before an incremental implementation nationwide.
- Build on work already undertaken locally.
- Enable the testing, refinement and validation of self-assessment tools and processes on a small scale with lower risk service users in the first instance
- Introduce self-assessment with the least disruption to existing processes and workforce configurations
- Engage stakeholders in the co-development of self-assessment tools and processes that are relevant to the New Zealand context, thereby -
- Enhance the partnership approach in the current NASC framework and standards
- Allow for a comparative analysis against the existing model
- Ensure that the ongoing development of self-assessment is aligned with the evolving development and implementation of the new model/framework, in particular the work in the demonstration site.

Phase one: Pilot self assessment in the demonstration site, within current NASC processes, as an option for service users with low-medium needs, specifically

The purpose of the first phase is to pilot self-assessment in a controlled manner within the demonstration site to manage risk. Whilst it is accepted that, in the long-term, it is preferable to avoid the ‘exclusion’ of any groups, the literature clearly indicates that self-assessment is not desired by everyone and that for some groups it is especially problematic.

It is recommended that the pilot includes only service users with low-medium need. Given the research evidence it would not be advisable to implement self-assessment for those with high-complex needs until the tools and processes have been fully developed, tested, and validated. The extension of self-assessment to the later group should be left until the third phase, by which time the new model/framework should be more fully developed and understood. It is also recommended that self assessment for children, or others who can not communicate or respond on their own behalf, is not included until the third phase.

It is important to clearly define the low-medium client group or cohort for whom the self-assessment option will be made available. Because of the difficulty associated with defining level of need prior to an assessment, it is advisable to focus on needs that can be more readily objectively defined. These are likely to be more the task-oriented domains of household support, and personal cares. A similar approach is used by FOCUS for requiring assistance with housework only. International literature also shows that self assessment has been successfully utilised for the provision of minor equipment and adaptations.

The work of already undertaken by LIFE Unlimited in developing a self-assessment process and associated tools could form the basis of the initial development work in the demonstration site. There may be intellectual property and commercial sensitivity issues that will need to be negotiated to enable this.

Recommendation 2: that in the demonstration site self assessment is offered to service users with low-medium need, specifically those only requiring household support, personal cares and/or minor equipment and adaptations.

Whilst it is acknowledged that in current NASC practice level of need is determined by the assessment and that assessments are not made to predetermined outcomes or services, for the purposes of the pilot, the determination to offer self-assessment would be made at triage.

Anecdotal reports and some literature suggest that there is a degree of confusion amongst service users as to what self-assessment is and what it does. It appears that some are not making a clear distinction between self-assessment and self determination or individual funding. As this confusion poses a significant risk to the successful implementation and utilisation of self-assessment the following action is recommended.

Recommendation 3: that preliminary to phase 1, the Ministry of Health engage with the disability community -to clarify what service users are expecting self-assessment to deliver.

Within the literature review self-assessment was investigated as a specific, identifiable component of wider processes – in reality this is difficult to do as it is just one part of a much larger whole and needs to be considered within the wider context. The form and function of self-assessment tools and process are dependent on how the outcomes of self-assessment are going to be ratified and provided. The self-assessment tool would be developed as part of phase 1 work and would ideally build on the work already undertaken locally.

Recommendation 4: that a self-assessment questionnaire appropriate for New Zealand is developed building on work already undertaken locally and as an integrated piece of work in the co-development of the new model involving a wide range of stake holders, including NASC, service users and carers, providers, Maori and other ethnic groups.

Recommendation 5: that the self-assessment questionnaire is developed as a standard template against the New Zealand standards and criteria to ensure that these continue to be met in the self-assessment process.

The final format of the SAQ should be agreed in the co-development process within the demonstration site, but based on the literature review and stock take interviews, it us recommended that a self-assessment questionnaire should be:

- Fit for purpose. This includes the purpose of self-assessment and its relationship to other aspects of the new model such as IF and LAC
    - As noted above, the RAS underpinning the IF model will greatly influence the form and function of the self-assessment tool and process
    - The link to LAC is less obvious. LAC is focused on building and reinforcing natural and community supports and social capital than it is on the assessment (Bennett & Bijoux, 2009)
- Culturally appropriate and holistic (focused on all aspects of a person's life) and encompassing the needs of the person and their family
- In plain language, practical and easy to complete
    - The tick box, multiple choice approach (see above) is simple and easily standardised, but it is recommended that "comments" or "further information" boxes are also included for people to provide additional information
    - If the Ministry of Health require a standardised approach nationwide, the recommended option is to follow a standard template approach, such as that used across England with In Control providing a template/model SAQ that is then adapted by local authorities. The In Control model or template SAQ and the adapted version used by Hartlepool Borough Council are both attached in full as appendices 1 and 2.

The tool should include paper based, electronic and alternative mediums as deemed appropriate, however, it is important to note that the literature does not support a fully online assessment as suggested by the DeLoittes report, as this has not been the preferred option for service users and is less likely to lead to difficulties with completion and dissatisfaction.

Recommendation 6: that initially self-assessment would be paper-based with alternative mediums offered as tools and processes are refined and validated.

Implications of phase one:

- Minimal impact on current relationships, responsibilities and workforce configurations
- Utilises work already undertaken with the New Zealand context
- In effect this is simply an alternative method of assessment offered as an option to a defined group of service users. The internal processes and systems surrounding it will be relatively largely unaffected
- Some training will be required for NASC assessors who are those primarily affected by the inclusion of the self-assessment option as they will have an additional role in determining appropriateness for self-assessment
- Will require an expansion of the capabilities of Socrates to cater for the self-assessment option.

Phase two: Incrementally roll-out self assessment to other sites building on the lessons learnt from the demonstration site pilot.

In this phase the self assessment pilot will be extended beyond the demonstration site and incrementally rolled-out nation-wide. Unless the lessons learnt from the demonstration pilot indicate otherwise, the target groups will remain the same as in the demonstration site. By phase two the lessons learnt from the demonstration pilot will have been incorporated into a standard set of processes and tools for use elsewhere. The degree of adaptation possible at other sites will be a matter to be determined during the pilot phase.

Implications of phase two:

- Clear guidelines will be essential as self assessment is incrementally implemented nationwide.
- The way in which the new model is developed in the demonstration site will impact on this phase. The relationship between self-assessment, LAC and, in particular, IF needs to be determined and agreed. It may be appropriate, for example, for the LAC to facilitate a supported self-assessment. As noted elsewhere, the RAS underpinning the IF model will have a significant impact on the form and function if the self-assessment

Phase three: Extend the self-assessment option to service users with higher, more complex needs.

The purpose of phase three will be to extend the self-assessment option to the remaining service users, primarily those with high-complex needs, and to carers. In this group the risks are generally higher and support needs greater. Self-assessment for these service users is more likely to be supported or facilitated or a self-assessment completed on behalf of another, such as a child or someone with cognitive impairment.

Further into the future, once self-assessment has been trialled and validated, it may be appropriate to extend it use into other settings, such as primary care with practise nurses.

Implications of phase three:

Extending the self-assessment option to those with high-complex needs raises two significant issues that need to be addressed as part of the development and implementation of self-assessment.

- The capacity issue– does the person have the capacity to do all or some of the assessment, and what level of support is required for them to do so?
- How to ensure, even al low levels of need, that when a self-assessment is completed on behalf of someone else, such as a child or others who can not communicate or respond on their own behalf, that their needs are met as well as those of the carer and family, whilst militating against potential risk.

The Requirements for Implementing Self-assessment

Informed by the literature, in particular the work of the PSSRU (Challis et al., 2008a), and overseas experience (personal communications with John Waters and Michel Kendrick), the following are suggested as requirements for implementing self-assessment in New Zealand:

Clear policy and political mandate – shown by the commitment to demonstrating the new DSS model/framework and through clear links to current policy.

A clear and agreed understanding of the purpose of self-assessment is important to its implementation. Self assessment must be seen to provide an effective response to the issues it is intended to respond to. However the apparent confusion amongst some service users as to the purpose and function of self-assessment must poses a risk successful implementation.

Close links with existing services and relevance to the wider agenda is no guarantee of sustainability, but it is a necessary foundation to achieving this. This includes clarity around how self assessment links with the new developments in DSS, particularly IF. In England, the expense and effort to sustain IB projects was likely to be less for projects that operated alongside existing systems compared to those which were outside mainstream practice or only operated in part of the authority.

A partnership, co-development approach is particularly important in dealing with cultural and ethnic diversity. This requires active engagement of support networks and communities through partnership and collaboration with individuals, families, local organisations and the broader community.

Scale and complexity of change - less complex processes reflecting incremental shifts in practice appear to be more readily accepted into mainstream practice and are simpler to implement than more complex changes representing shifts in models of practice. The scale and complexity of change can be managed through a graduated approach with incremental changes that allows opportunities for evaluation, learning and adaptation. Such a phased approach is also endorsed by Lord and Hutchison (2003).

Management and leadership - Visible and ongoing senior management support and leaders who effectively engage and support staff and the wider community are essential to the successful implementation of innovation. Appropriate facilitating and supporting mechanisms are required to enable effective leadership.

Adaptability - flexibility and the ability to adapt to unforeseen circumstances is more likely to lead to successful implementation in the long term.

Challenging the culture – changing staff perceptions. Staff can be supported through a variety of means, but it is important to keep them informed of the changes and provide opportunities for them to voice their concerns. Training and involving staff directly in developing new processes can facilitate engagement in the project. A number of the IB pilot projects in England successfully utilised 'change champions' to lead the way in the change process. If used, change agents or champions must have credibility amongst those involved in implementing self-assessment.

Marketing and publicity are now accepted as having a role in public sector services as a means of learning about the public's experiences, perceptions and concerns about current services and to tailor future services to better meet the needs of service users. Successful implementation will also require the promotion of a culture of self-assessment amongst service users.

Use of information technology The ability to obtain appropriate IT systems and support is an important factor in the promotion of implementation. Whilst we are not supporting InterRai, there are lessons to be learnt from the development and implementation of InterRai in New Zealand. It is recommended that NASCs who have implemented InterRai are canvassed so that key lessons can be shared.

A robust, independent and ongoing evaluation should accompany the implementation process. The evaluation should be comprehensive and where possible, compare self-assessment with traditional forms of assessment and include:

- Outcomes for and experiences of service users and carers (this could include consumer satisfaction questions as part of the self-assessment questionnaire)
- The views and experiences of staff involved in self-assessment
- Cost-effectiveness including financial risks
- Efficacy of the self-assessment process in terms types and number of services accessed, time taken between steps in the process, degree of professional input in self-assessments.

Recommendation 7: -that the effectiveness of self-assessment is formally evaluated in the demonstration then in each site as it is incrementally implemented.

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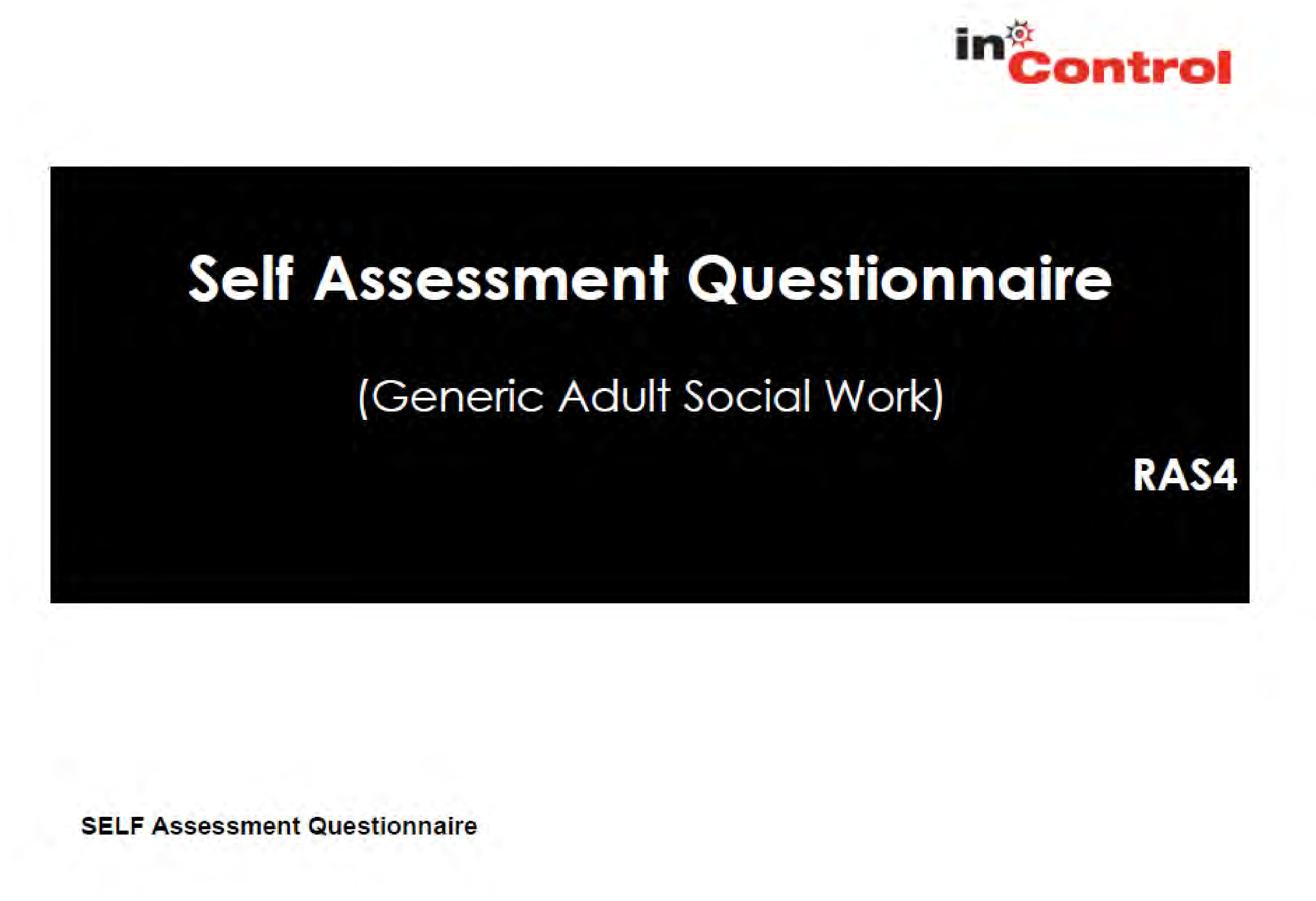
Appendices

Appendix 1: In Control model SAQ



Self Assessment Questionnaire

(Generic Adult Social Work)

RAS4

SELF Assessment Questionnaire

2 Relationships

This part is about friendships and people I know – not just my family.

		Points	Outcomes
A) I don't really have any relationships outside my family. I need support to make relationships – and keep them	☐	3	For me to form a friendship or relationship outside of family or people paid to be with me.
B) I have one or two relationships – but not enough for me. I need support to make relationships – and keep them.	☐	2	For me to form more friendships or relationships outside of family or people paid to be with me
C) I've got a lot of relationships – the right number for me. I need a bit of support to keep them.	☐	1	To keep in touch with people who are important to me.
D) I've got a lot of relationships. I don't need support to keep them. I don't want to make anymore relationship than I have presently.	☐	0	

3 Being part of the local community

This part is about doing things in my community – like using local shops, the library, going to the cinema, clubs, community centre, church or other place of worship, helping neighbours, or being involved in local organisations.

		Points	Outcomes
A) I don't do much in outside of my home in the community. I need support to do more.	☐	3	To do things in and be part of my community
B) Sometimes I do things outside of my home in the community. I need support to do more.	☐	2	To do more things in and contribute more to my community.
C) I do lots of things in outside of my home in the community. I need support to do them.	☐	1	To remain active in my community
D) I do lots of things in my community. I don't need support. I do not want to or I am unable to do much out side of my home.	☐	0	

4 Work, leisure and learning

This part is about having a job, learning new things and enjoying life.

		Points	Outcomes
A) I don't have many chances to work, or learn new things, or enjoy life. I need support to do these more.	☐	3	To work and have a Job, to gain new skills.
B) I have a few chances to work, learn new things, and enjoy life. I need support to do these more.	☐	2	To have more chances to work and take part in ongoing learning.
C) I am busy – with a job or learning new things – and I enjoy my spare time. I need support to keep these going.	☐	1	To carry on working and learning
D) I am busy and enjoy my spare time. I have the support I need to keep these going – from family, friends or workmates. I am of retirement age and feel that I am ok without this support.	☐	0	

5 Making Decisions

This part is about who decides important things in my life – things like where I live, who supports me, who looks after my money.

		Points	Outcomes
A) Other people make most decisions about my life. I need support to make more decisions.	☐	3	To take more decisions about things important to me.
B) I decide most day-to-day things. But I don't have as much say in important decisions about my life. I need support.	☐	2	To take the decisions that are important to me.
C) I make all the decisions. I need support and advice to make them.	☐	1	To carry on making decisions with good advice
D) I make all the decisions. I just need a bit of advice. Or I am in a residential home.	☐	0	

6 Staying safe from harm

This part is about keeping safe when I'm going out on a bus, or using a gas cooker, or going down stairs. Those are the things that are important for me. But staying safe is about different things for different people.

		Points	Outcomes
A) I need help to stay safe a lot of the time. People worry a lot about my safety. Or I am in a residential placement.	☐	15	To be safe and free from harm
B) I need help to stay safe some of the time. People worry a bit about my safety.	☐	4	To be safe and free from harm
C) Sometimes I need a bit of help to stay safe. I'm happy and no-one says they're worried.	☐	2	To be safe and free from harm
D) I don't need help to stay safe. I'm happy and no-one says they're worried.	☐	0	

7 Complex needs and risks

This part is about my behaviour – the things I do. Can my behaviour be dangerous for me or other people?

		Points	Outcomes
A) I often do things that could hurt me or other people. People have tried to help me change what I do. But there's still a risk I could hurt myself or other people.	☐	15	To be free from harm and not cause harm to others
B) I often do things that could hurt me or other people. People have helped me change what I do. There's not a big risk I could hurt myself or other people.	☐	10	To be free from harm and not cause harm to others
C) Some things I do are a problem for other people. But there's no real danger to me or other people.	☐	5	To be free from harm and not cause harm to others
D) In the past I've done things that could hurt me or others. Or I've done things that were a problem for other people. But there's no problem now.	☐	3	To be free from harm and not cause harm to others
E) I've never done things that could hurt me or others. People around me support me well.	☐	0	

8(a) Family carer and social support

My family carer
This part is for my family carer. What does supporting me mean for my family carer? What is their life like?
To the family carer:
This part is for you. To answer this question you need to imagine you are caring full-time for your family member – even if you're not; even if your family member has support.

		Points	Outcomes
A) My caring role has a critical impact on my lifestyle - including a significant impact on my health and well-being. I am unwilling or unable to continue in the role as it currently is. (Resuming a greater caring role would have this effect)	☐	15	For my caring role to change so that It no longer has such a detrimental impact on my life.
B) My caring role has a substantial impact on my lifestyle. Playing this role has led to high levels of stress and some health problems.(Resuming a greater caring role would have this effect)	☐	10	For my caring role to change so that It no longer has such a detrimental impact on my life.
C) I have some difficulty and stress in carrying out my day-to-day caring tasks. There is some impact on my lifestyle and playing this role leads to minor stress. (Resuming a greater caring role would have this effect)	☐	7	For me to feel supported to carry on in my caring role.
D) I am able and willing to continue in my current caring role. My caring responsibilities have only a small impact on my daily life.(I would like to play a greater caring role than I currently do, and have some time to provide support)	☐	5	For me to feel supported to carry on in my caring role.
E) I am able and willing to continue in my current caring role. My caring responsibilities have no negative impact on my daily life (I would like to play a far greater caring role than I currently do, and have time to provide support) Or I have no carer and/or I am in a residential placement.	☐	0	

8(b) Family carer and social support

A X B

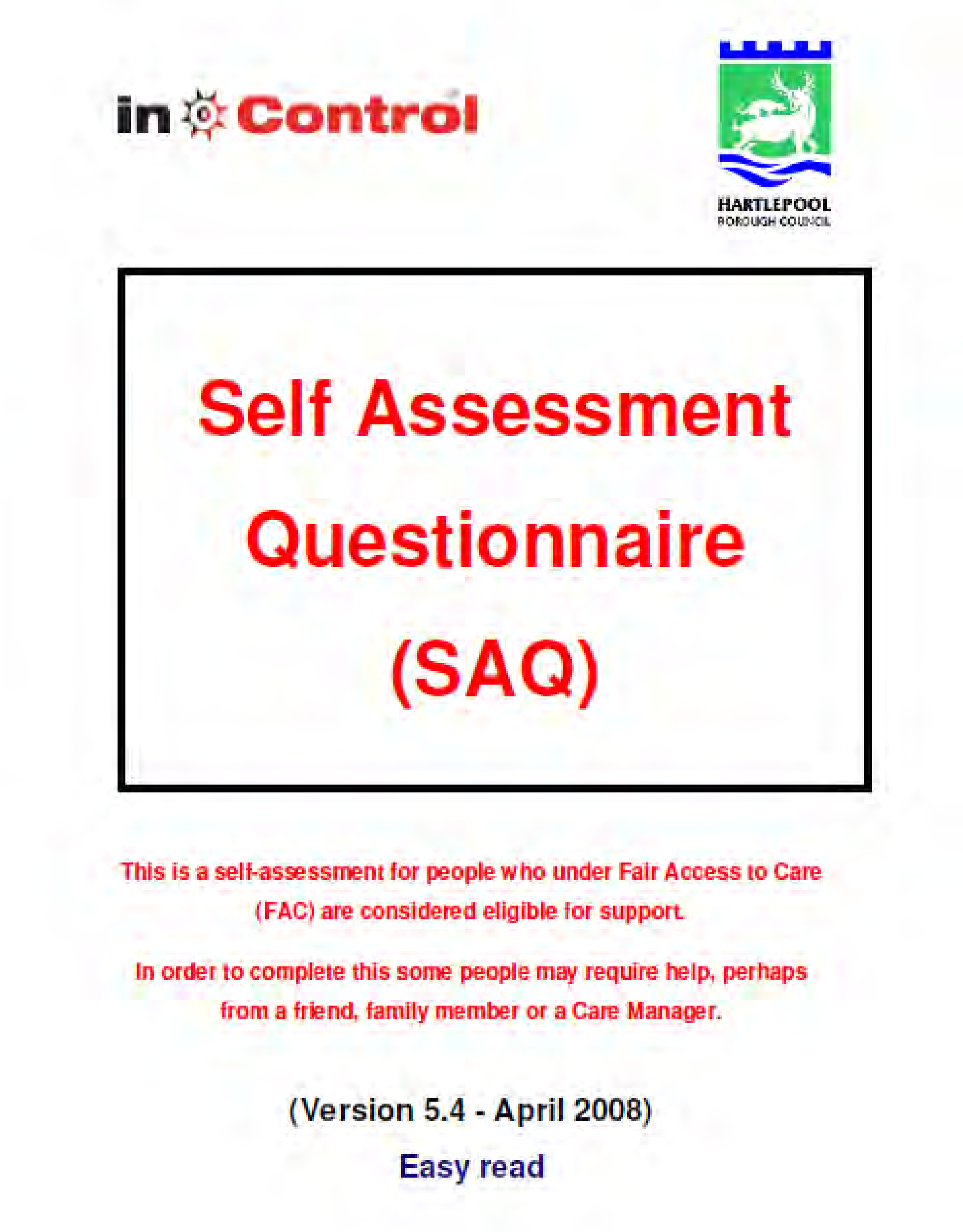
1	I am able to get nearly all the help I need from my family and friends or I am in a residential placement 1	I currently need no paid support 0
2	I am able to get most of the help I need from family and friends 2	I have or need some occasional paid help 2
3	I am able to get only some of the help I need from family and friends 3	I have or need ongoing regular help 3
4	I can get little or no help at all from family or friends 4	I have lots of paid support Full time day care Respite I currently have 24 paid support 4

	B1	B2	B3	B4
A1	0	2	3	4
A2	0	4	6	8
A3	0	6	9	12
A4	0	8	12	16

If you would like a full version of In Control's Resource Allocation System or to know more about in Control, visit our website:

www.in-control.org.uk

Appendix 2: Hartlepool SAQ



in Control

HARTLEPOOL
BOROUGH COUNCIL

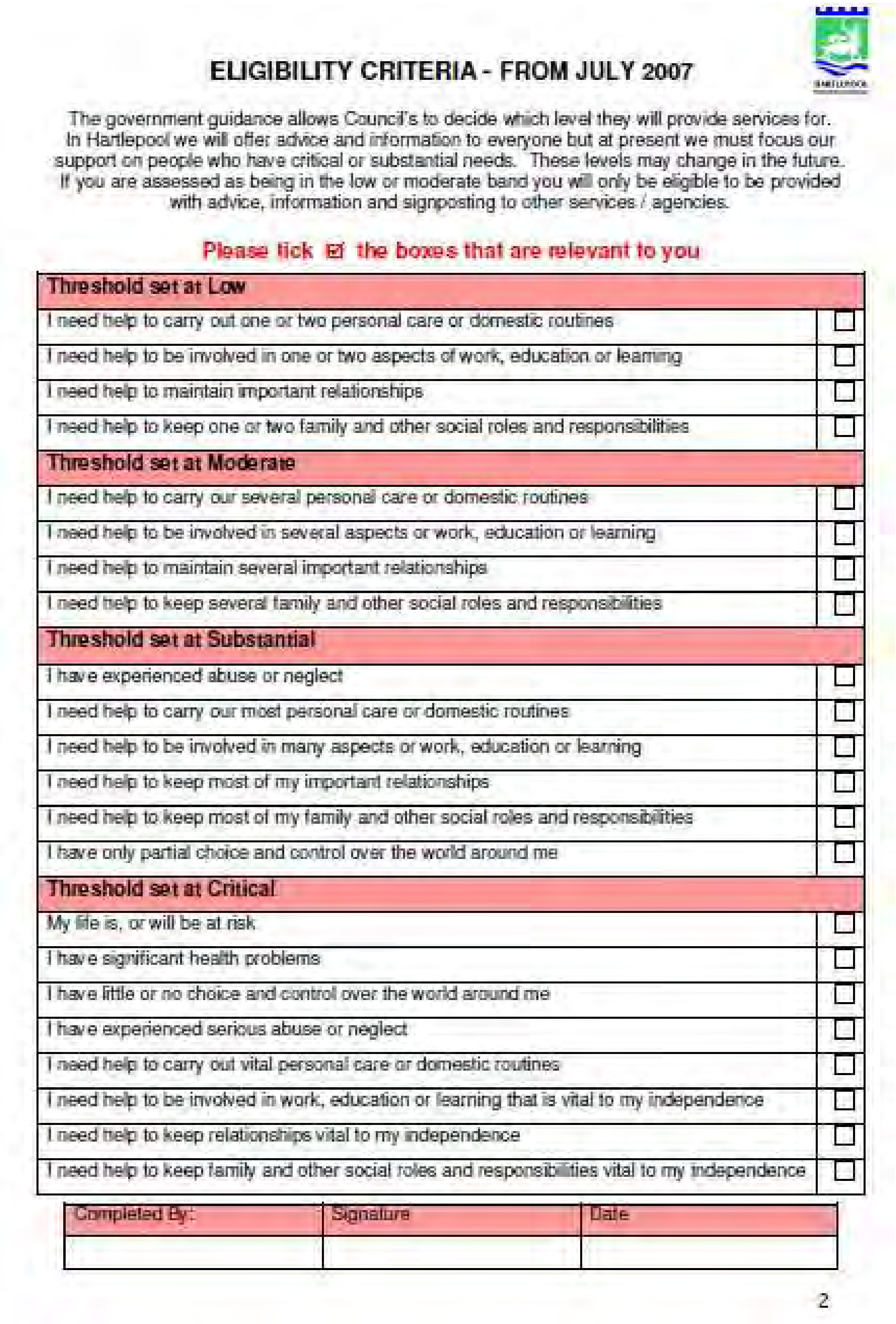
Self Assessment Questionnaire (SAQ)

This is a self-assessment for people who under Fair Access to Care (FAC) are considered eligible for support.

In order to complete this some people may require help, perhaps from a friend, family member or a Care Manager.

(Version 5.4 - April 2008)

Easy read



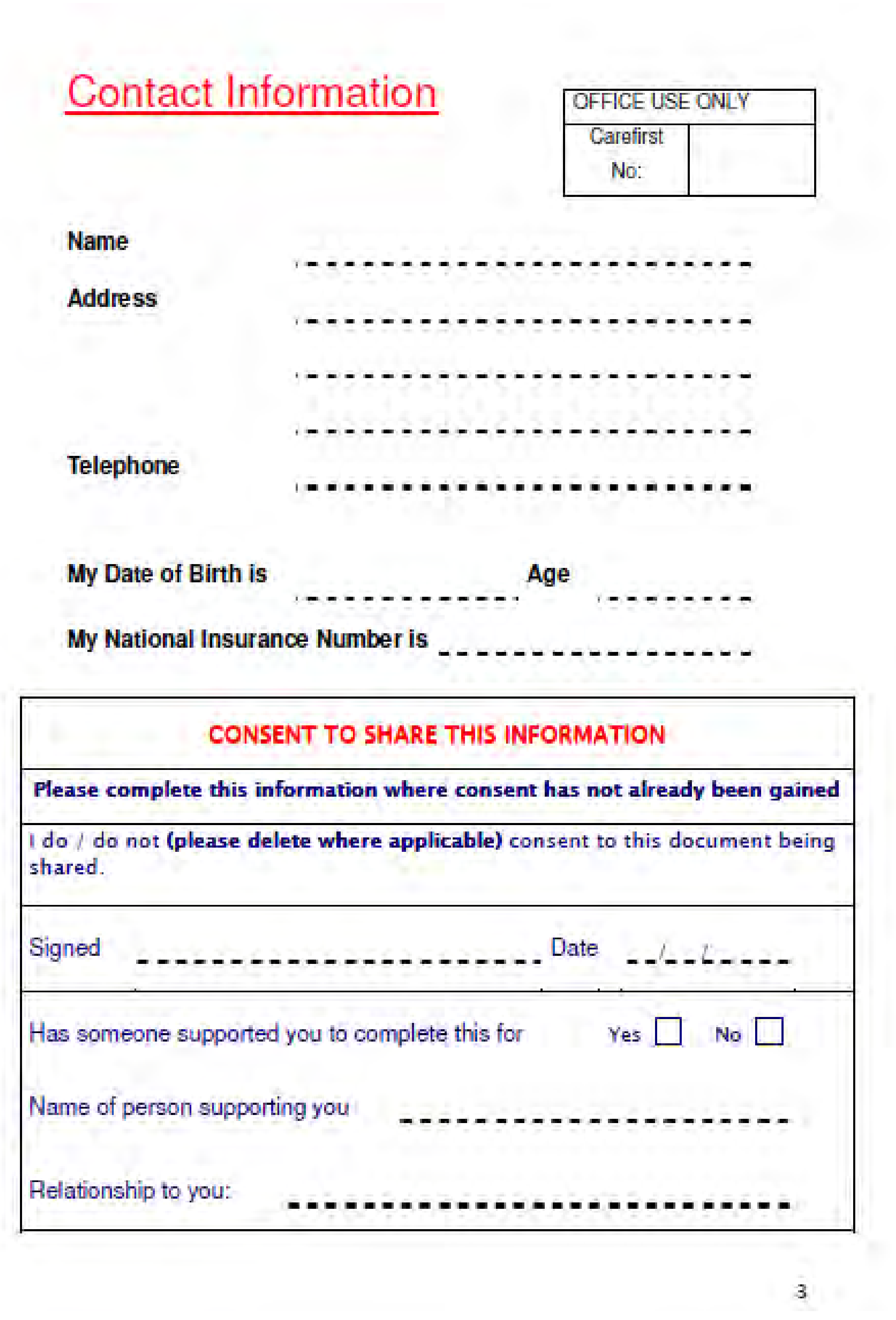
ELIGIBILITY CRITERIA - FROM JULY 2007

The government guidance allows Council's to decide which level they will provide services for. In Hartlepool we will offer advice and information to everyone but at present we must focus our support on people who have critical or substantial needs. These levels may change in the future. If you are assessed as being in the low or moderate band you will only be eligible to be provided with advice, information and signposting to other services / agencies.

Please tick ☑ the boxes that are relevant to you

Threshold set at Low	
I need help to carry out one or two personal care or domestic routines	☐
I need help to be involved in one or two aspects of work, education or learning	☐
I need help to maintain important relationships	☐
I need help to keep one or two family and other social roles and responsibilities	☐
Threshold set at Moderate	
I need help to carry our several personal care or domestic routines	☐
I need help to be involved in several aspects or work, education or learning	☐
I need help to maintain several important relationships	☐
I need help to keep several family and other social roles and responsibilities	☐
Threshold set at Substantial	
I have experienced abuse or neglect	☐
I need help to carry our most personal care or domestic routines	☐
I need help to be involved in many aspects or work, education or learning	☐
I need help to keep most of my important relationships	☐
I need help to keep most of my family and other social roles and responsibilities	☐
I have only partial choice and control over the world around me	☐
Threshold set at Critical	
My life is, or will be at risk	☐
I have significant health problems	☐
I have little or no choice and control over the world around me	☐
I have experienced serious abuse or neglect	☐
I need help to carry out vital personal care or domestic routines	☐
I need help to be involved in work, education or learning that is vital to my independence	☐
I need help to keep relationships vital to my independence	☐
I need help to keep family and other social roles and responsibilities vital to my independence	☐

Completed By:	Signature	Date



Contact Information

OFFICE USE ONLY	
Carefirst No:	

Name ------------------------

Address ------------------------

Telephone ------------------------

My Date of Birth is ------------ **Age** --------

My National Insurance Number is ----------------

CONSENT TO SHARE THIS INFORMATION
Please complete this information where consent has not already been gained
I do / do not **(please delete where applicable)** consent to this document being shared.
Signed ------------------------ Date --/--/----
Has someone supported you to complete this for Yes ☐ No ☐ Name of person supporting you ---------------------- Relationship to you: ----------------------------

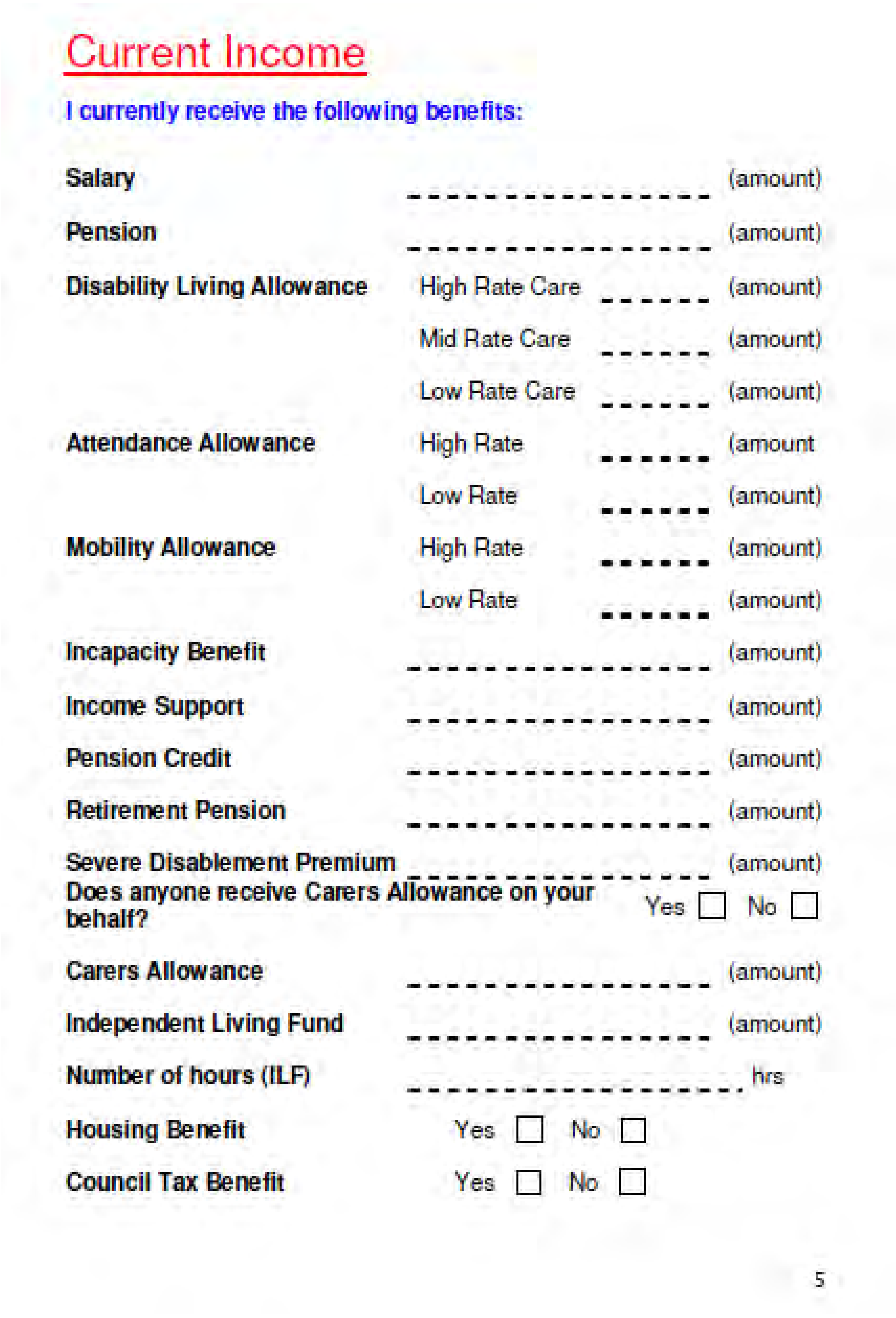
3

Current support

I currently get support from:

TICK THE BOX THAT FITS YOU BEST ☑

• Family, friends or neighbours	☐
• Adult & Community Services	☐
• Health Services	☐
• Other Please specify	☐



Current Income

I currently receive the following benefits:

Salary		________________	(amount)
Pension		________________	(amount)
Disability Living Allowance	High Rate Care	______	(amount)
	Mid Rate Care	______	(amount)
	Low Rate Care	______	(amount)
Attendance Allowance	High Rate	______	(amount
	Low Rate	______	(amount)
Mobility Allowance	High Rate	______	(amount)
	Low Rate	______	(amount)
Incapacity Benefit		________________	(amount)
Income Support		________________	(amount)
Pension Credit		________________	(amount)
Retirement Pension		________________	(amount)
Severe Disablement Premium		________________	(amount)

Does anyone receive Carers Allowance on your behalf? Yes ☐ No ☐

Carers Allowance	________________	(amount)
Independent Living Fund	________________	(amount)
Number of hours (ILF)	________________	hrs

Housing Benefit Yes ☐ No ☐

Council Tax Benefit Yes ☐ No ☐

Savings and property

Do you currently have savings over	£13,000	Yes ☐	No ☐
	£21,500	Yes ☐	No ☐
Do you live alone?		Yes ☐	No ☐
Do you have a partner?		Yes ☐	No ☐
Do you own your home?		Yes ☐	No ☐
Do you own any other property or land?		Yes ☐	No ☐

Accommodation

What type of accommodation do you live in? (e.g. sheltered accommodation, supported living, mortgaged/owned home)

Do you have difficulties within the property?

Is there any reason why you need to change your living situation?

Do you hold a tenancy for your home? Yes ☐ No ☐

Do you have/need any minor aids/equipment/adaptations to your home to make it easier for you to move around? (eg grab rails etc)

Do you have/need any major aids/adaptations to your home? (eg stair lift, ramp etc)

Are you deaf/hearing impaired? Yes ☐ No ☐

If yes, please provide further information - - - - - - - - - - - - - - - -

Are you blind/visually impaired? Yes ☐ No ☐

If yes, please provide further information - - - - - - - - - - - - - - - -

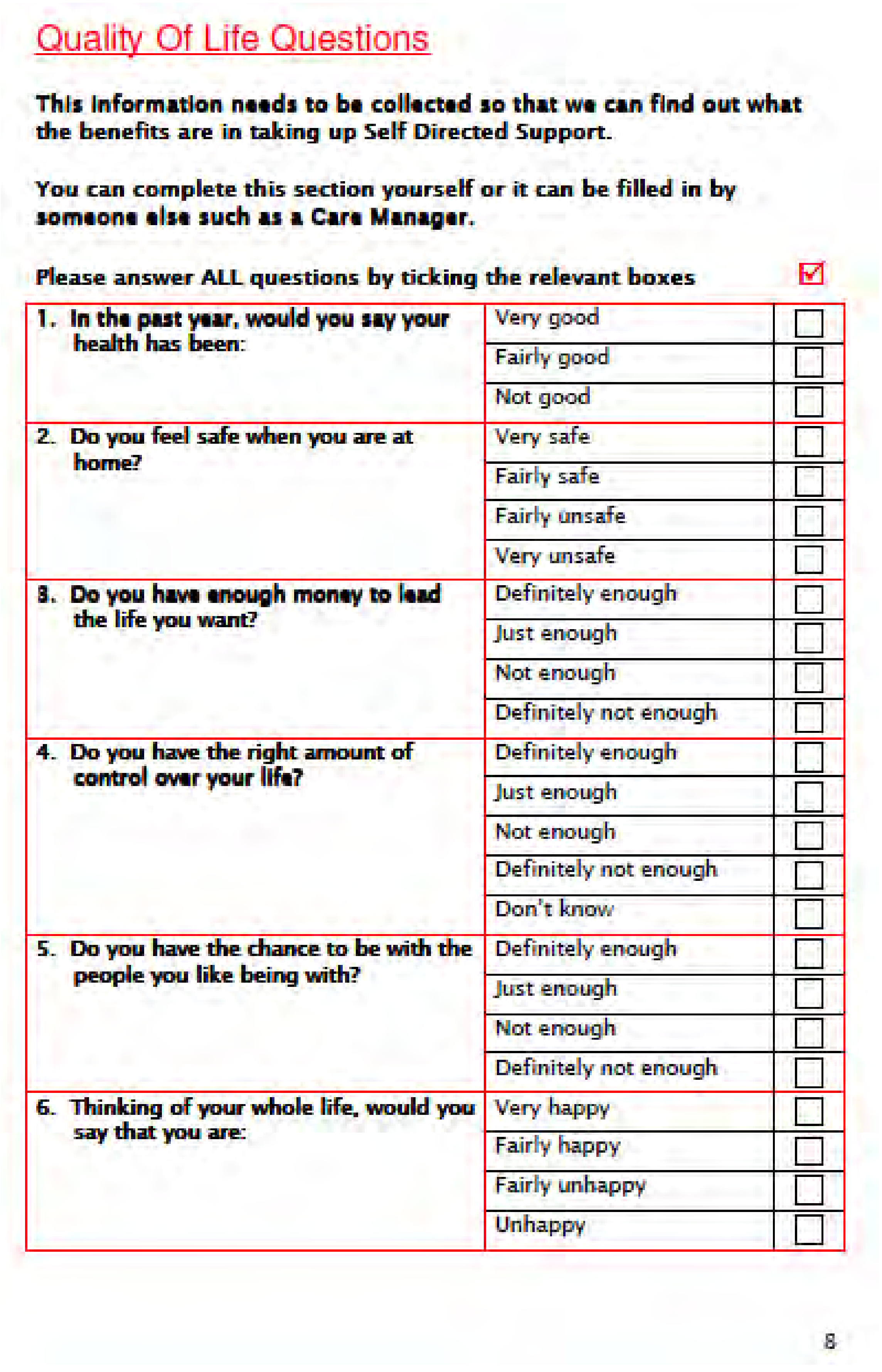
Do you need help to communicate, help from an interpreter or to understand what is said to you? Yes ☐ No ☐

If yes, please provide further information - - - - - - - - - - - - - - - -

Are you a wheelchair user? Yes ☐ No ☐

If yes, please provide further information - - - - - - - - - - - - - - - -

The Resource Allocation System is designed to assess how having support needs affects your day-to-day life. It is not just about how your disability affects you but is about the life you lead at present.



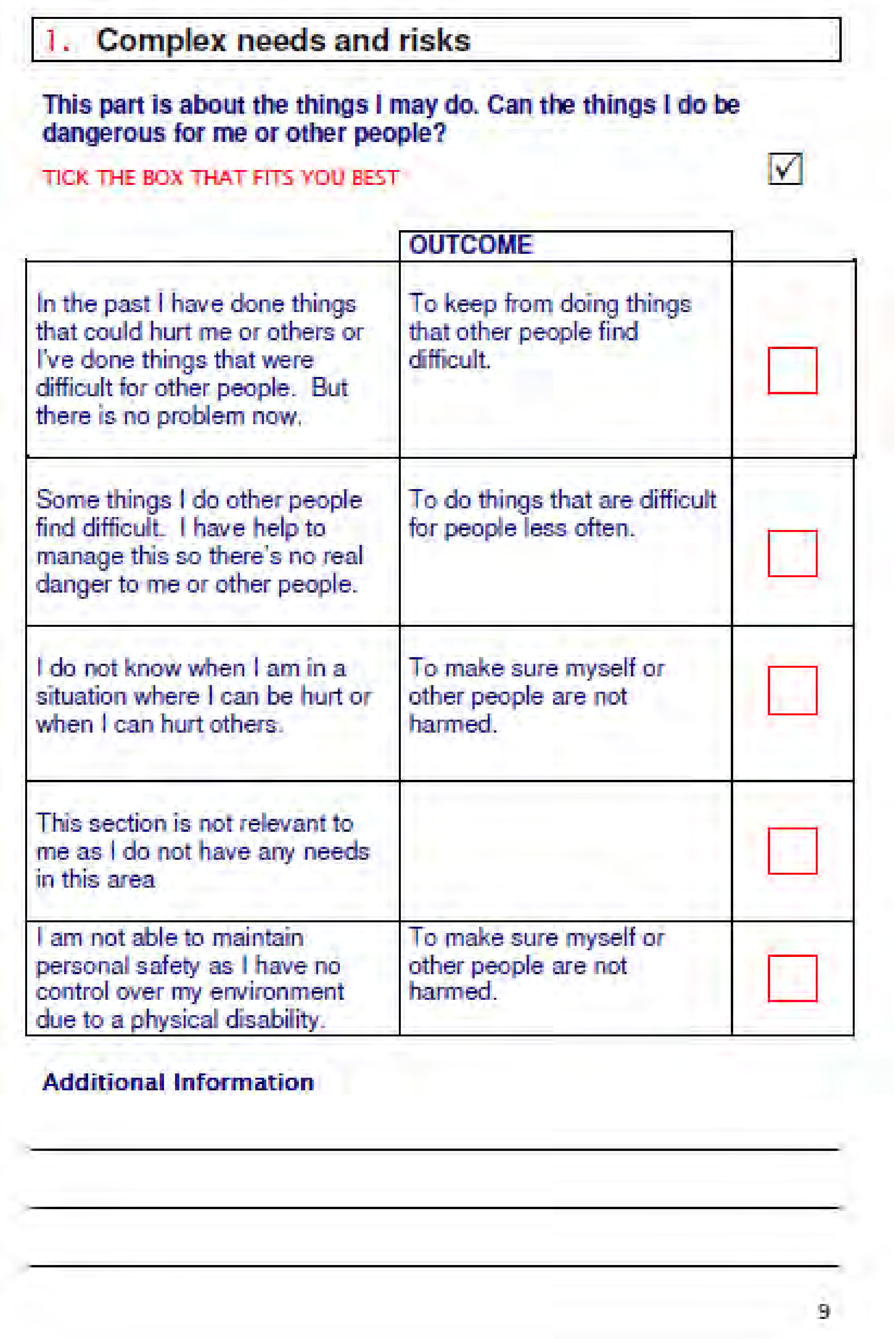
Quality Of Life Questions

This information needs to be collected so that we can find out what the benefits are in taking up Self Directed Support.

You can complete this section yourself or it can be filled in by someone else such as a Care Manager.

Please answer ALL questions by ticking the relevant boxes ☑

1. In the past year, would you say your health has been:	Very good	☐
	Fairly good	☐
	Not good	☐
2. Do you feel safe when you are at home?	Very safe	☐
	Fairly safe	☐
	Fairly unsafe	☐
	Very unsafe	☐
3. Do you have enough money to lead the life you want?	Definitely enough	☐
	Just enough	☐
	Not enough	☐
	Definitely not enough	☐
4. Do you have the right amount of control over your life?	Definitely enough	☐
	Just enough	☐
	Not enough	☐
	Definitely not enough	☐
	Don't know	☐
5. Do you have the chance to be with the people you like being with?	Definitely enough	☐
	Just enough	☐
	Not enough	☐
	Definitely not enough	☐
6. Thinking of your whole life, would you say that you are:	Very happy	☐
	Fairly happy	☐
	Fairly unhappy	☐
	Unhappy	☐



1. Complex needs and risks

This part is about the things I may do. Can the things I do be dangerous for me or other people?

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
In the past I have done things that could hurt me or others or I've done things that were difficult for other people. But there is no problem now.	To keep from doing things that other people find difficult.	☐
Some things I do other people find difficult. I have help to manage this so there's no real danger to me or other people.	To do things that are difficult for people less often.	☐
I do not know when I am in a situation where I can be hurt or when I can hurt others.	To make sure myself or other people are not harmed.	☐
This section is not relevant to me as I do not have any needs in this area		☐
I am not able to maintain personal safety as I have no control over my environment due to a physical disability.	To make sure myself or other people are not harmed.	☐

Additional Information

2. Meeting personal needs

This part is about looking after myself – things like washing, getting up out of bed, going to the toilet, dressing and personal support needs

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I am able to meet my personal needs and do not require any support in this area.		☐
I am able to meet my personal care needs with occasional physical / gestural / verbal support.	To maintain independence but ensure essential care needs are met	☐
I need significant physical / gestural / verbal support from another to meet my personal care needs.	To have essential personal care needs met and remain free from harm	☐
I need full intimate support to meet my personal support needs. I need this from someone else.	To have essential personal care needs met and remain free from harm	☐

Additional information

3. Meals and Nutrition

This part is about the help that I may need to help me to stay healthy

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I do not need any help in this area.		☐
I need **some** help with preparing meals.	To acquire increased independence and remain well nourished.	☐
I need **all** of my meals provided or prepared for me by someone else.	To remain well nourished and free from harm.	☐
I need **total support** from someone else to help me to prepare my meals and to help me to eat and drink.	To remain well nourished and free from harm.	☐

Additional information

4. Work, Learning and Leisure

This part is about having a job, learning new things or keeping busy and enjoying life (including vocational activities).

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I do not need any help in this area.		☐
I have a work role / job / am enjoying my spare time. This gives meaning and purpose in my life and I need some support to keep this.	To keep work leisure activities going.	☐
I need support to take part in work, leisure or learning. I need more support to get more opportunities for work, learning or leisure.	To take part in work leisure or learning.	☐
I need support to take part in work, leisure and learning and I have few or no chances for work, leisure or learning in my life.	To take part in work leisure or learning.	☐

Additional Information

____

____

____

5. Making important decisions about life

This part is about who decides important things in my life – things like where I live and who supports me

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I do not need any support in this area.		☐
I need support to make decisions but I have full control over all day-to-day and life changing decisions.	To maintain opportunities to make supported decisions.	☐
I need support to make decisions. I have control over most day-to-day decisions but less say in life changing decisions.	To have control over life changing decisions.	☐
I need support to make decisions about my life, but most day-to-day decisions are taken by other on my behalf.	To take more control over day-to-day decisions.	☐

Additional Information

____

____

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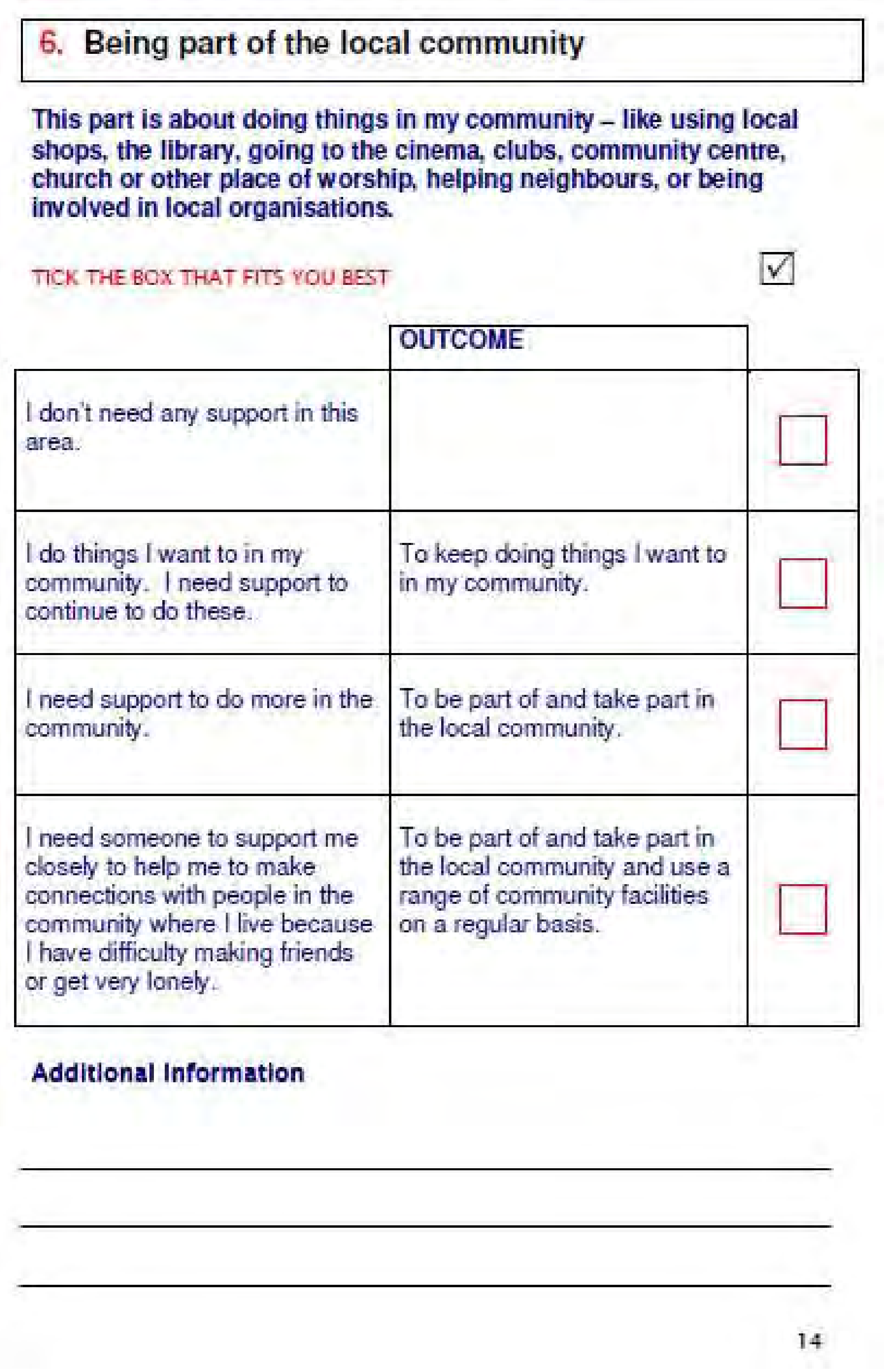


6. Being part of the local community

This part is about doing things in my community – like using local shops, the library, going to the cinema, clubs, community centre, church or other place of worship, helping neighbours, or being involved in local organisations.

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I don't need any support in this area.		☐
I do things I want to in my community. I need support to continue to do these.	To keep doing things I want to in my community.	☐
I need support to do more in the community.	To be part of and take part in the local community.	☐
I need someone to support me closely to help me to make connections with people in the community where I live because I have difficulty making friends or get very lonely.	To be part of and take part in the local community and use a range of community facilities on a regular basis.	☐

Additional information

____

____

____

14

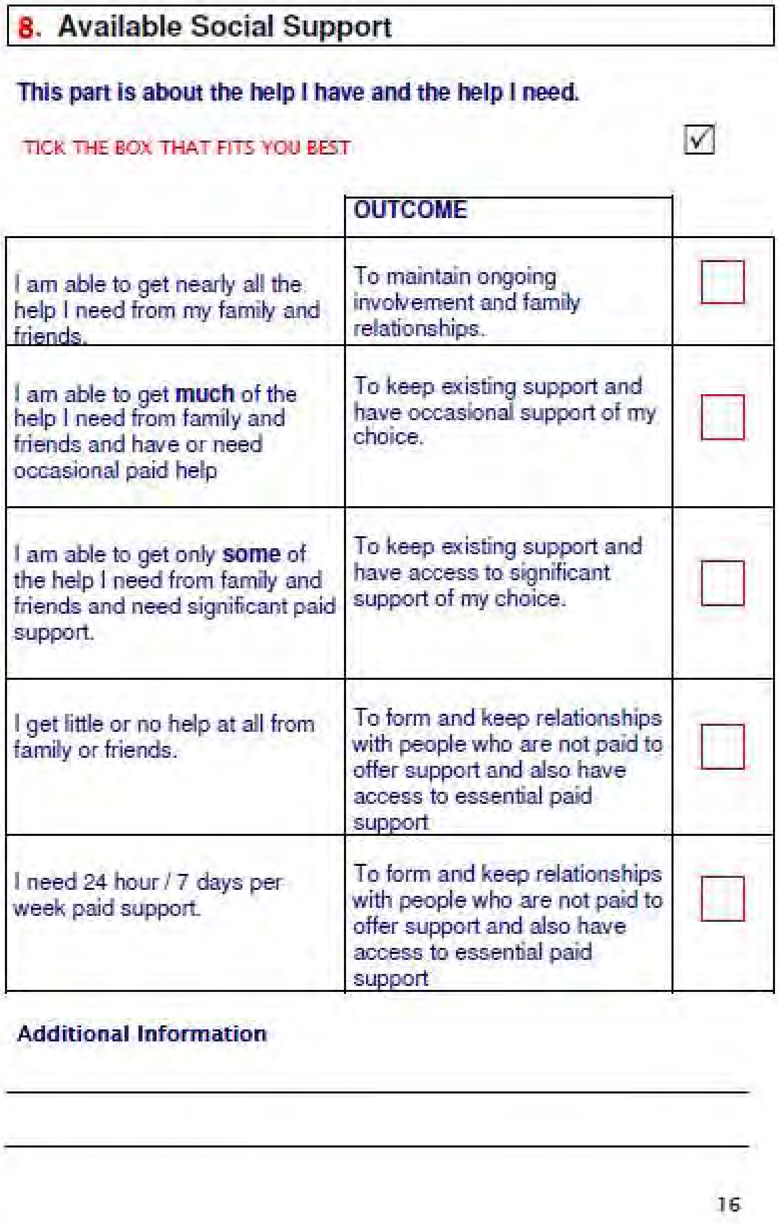
7. Essential Family / Caring Role

This section is about the help that I may need to care for someone who needs my help, e.g. child or a dependant. For example, Parent, sibling, partner, grandparent, other family member, friend etc.

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I do not need any support with my parenting / caring role or am not a parent.		☐
I need some support with parenting tasks, or some support in my role as a carer.	To maintain current parent / carer role	☐
I need lots of support with many parenting tasks, or a lot of support in my role as a carer.	To reduce impact of caring and maintain current caring role.	☐

Additional information



8. Available Social Support

This part is about the help I have and the help I need.

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I am able to get nearly all the help I need from my family and friends.	To maintain ongoing involvement and family relationships.	☐
I am able to get **much** of the help I need from family and friends and have or need occasional paid help	To keep existing support and have occasional support of my choice.	☐
I am able to get only **some** of the help I need from family and friends and need significant paid support.	To keep existing support and have access to significant support of my choice.	☐
I get little or no help at all from family or friends.	To form and keep relationships with people who are not paid to offer support and also have access to essential paid support	☐
I need 24 hour / 7 days per week paid support.	To form and keep relationships with people who are not paid to offer support and also have access to essential paid support	☐

Additional Information

____

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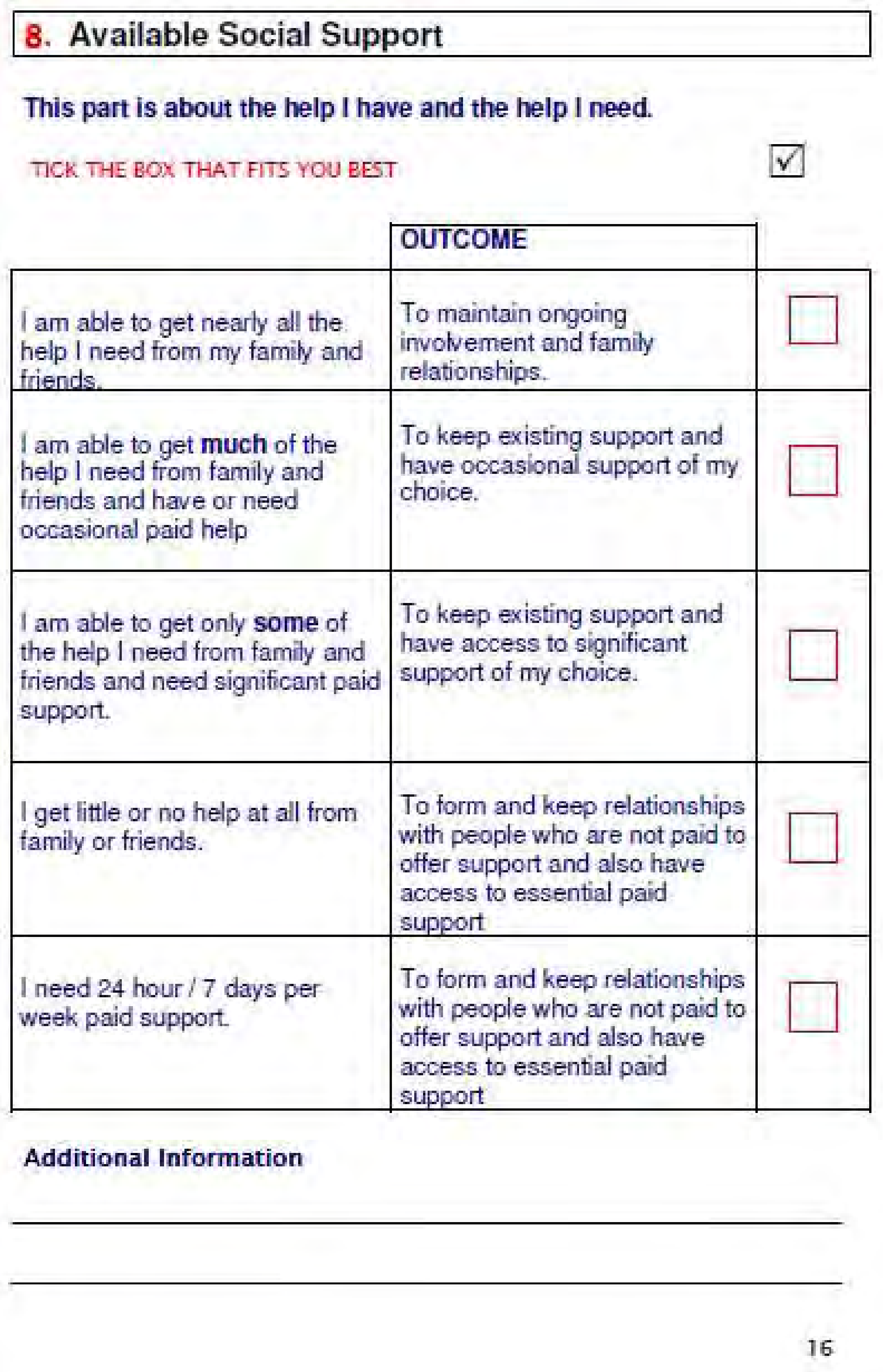


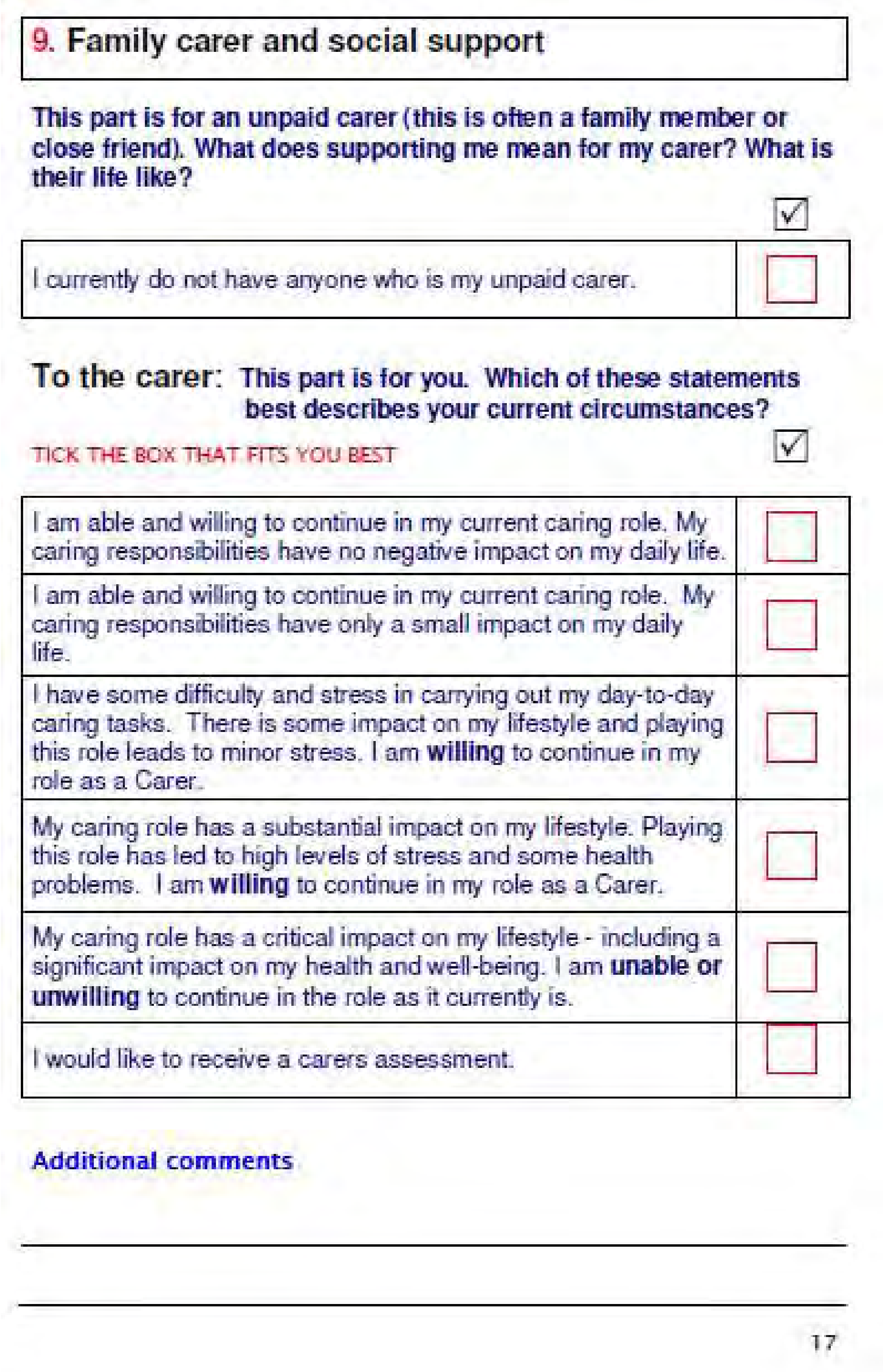
8. Available Social Support

This part is about the help I have and the help I need.

TICK THE BOX THAT FITS YOU BEST ☑

	OUTCOME	
I am able to get nearly all the help I need from my family and friends.	To maintain ongoing involvement and family relationships.	☐
I am able to get **much** of the help I need from family and friends and have or need occasional paid help	To keep existing support and have occasional support of my choice.	☐
I am able to get only **some** of the help I need from family and friends and need significant paid support.	To keep existing support and have access to significant support of my choice.	☐
I get little or no help at all from family or friends.	To form and keep relationships with people who are not paid to offer support and also have access to essential paid support	☐
I need 24 hour / 7 days per week paid support.	To form and keep relationships with people who are not paid to offer support and also have access to essential paid support	☐

Additional Information



9. Family carer and social support

This part is for an unpaid carer (this is often a family member or close friend). What does supporting me mean for my carer? What is their life like?

	☑
I currently do not have anyone who is my unpaid carer.	☐

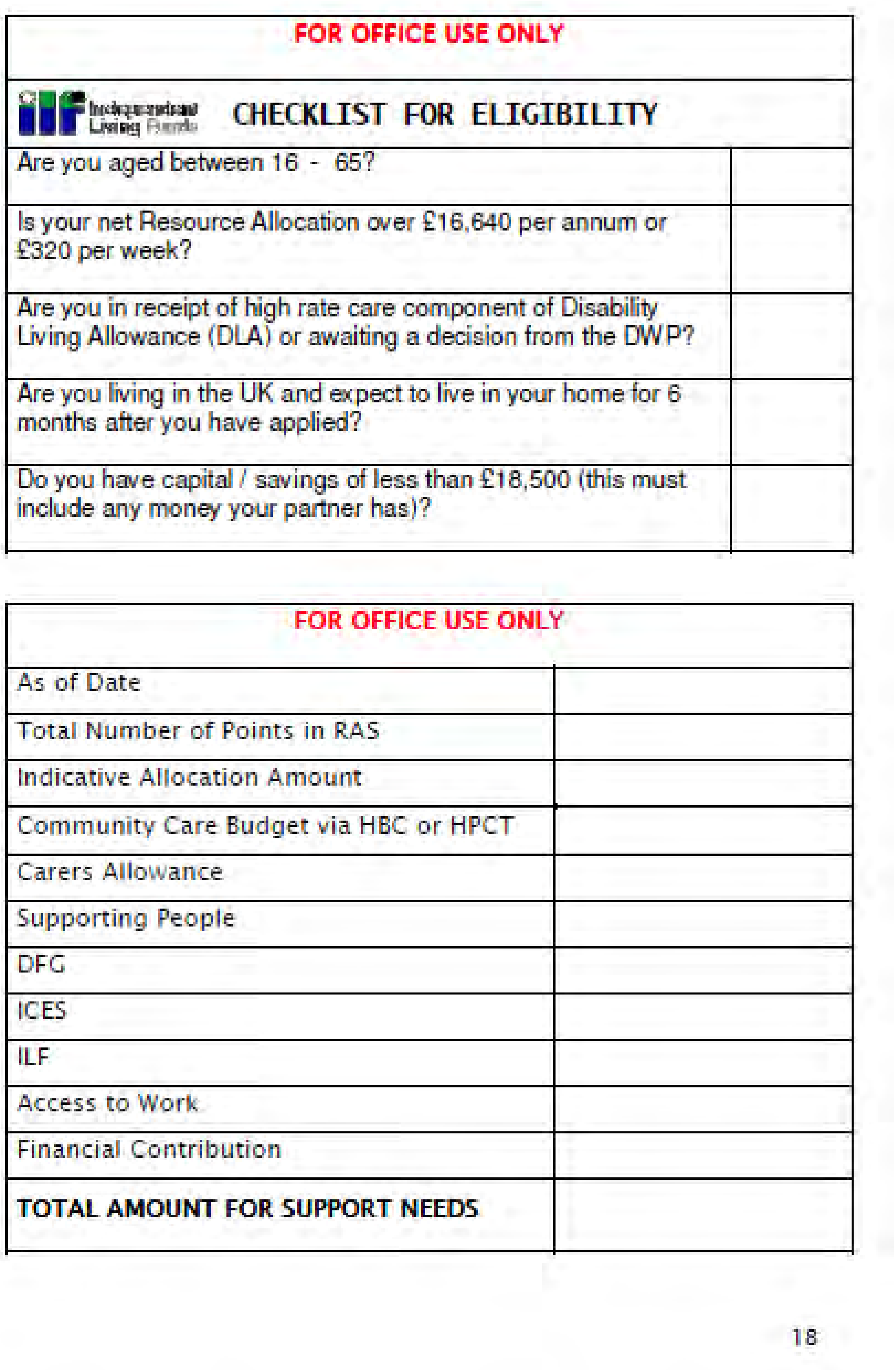
To the carer: **This part is for you. Which of these statements best describes your current circumstances?**

TICK THE BOX THAT FITS YOU BEST

	☑
I am able and willing to continue in my current caring role. My caring responsibilities have no negative impact on my daily life.	☐
I am able and willing to continue in my current caring role. My caring responsibilities have only a small impact on my daily life.	☐
I have some difficulty and stress in carrying out my day-to-day caring tasks. There is some impact on my lifestyle and playing this role leads to minor stress. I am **willing** to continue in my role as a Carer.	☐
My caring role has a substantial impact on my lifestyle. Playing this role has led to high levels of stress and some health problems. I am **willing** to continue in my role as a Carer.	☐
My caring role has a critical impact on my lifestyle - including a significant impact on my health and well-being. I am **unable or unwilling** to continue in the role as it currently is.	☐
I would like to receive a carers assessment.	☐

Additional comments

17



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CHECKLIST FOR ELIGIBILITY

Are you aged between 16 - 65?	
Is your net Resource Allocation over £16,640 per annum or £320 per week?	
Are you in receipt of high rate care component of Disability Living Allowance (DLA) or awaiting a decision from the DWP?	
Are you living in the UK and expect to live in your home for 6 months after you have applied?	
Do you have capital / savings of less than £18,500 (this must include any money your partner has)?	

FOR OFFICE USE ONLY

As of Date	
Total Number of Points in RAS	
Indicative Allocation Amount	
Community Care Budget via HBC or HPCT	
Carers Allowance	
Supporting People	
DFG	
ICES	
ILF	
Access to Work	
Financial Contribution	
TOTAL AMOUNT FOR SUPPORT NEEDS	

Appendix 3: List of stock-take interviewees

Name	Position	Organisation
Judy Bilderbeck	CEO	AccessAbility
David Darling	Service Leader	Capital Support
Helene Dore	Team Leader	Focus
Rosalie Eilering (& Kay Thomas)	Manager NASC	NorthAble
Ann Fowler (& Raewyn Cameron)	Manager	Supportlinks
Sue Hansson	Manager	Access Ability
Sonia Hawea	Chief Executive	Taikura Trust (INSA)
Marlon Hepi	Senior Leader: Tairawhiti & Petone	LIFE Unlimited
Kim Holt	Manager	Disability Support Link
Craig Hutchison	Managing Director	Life Links
Carole Kerr	District Manager	Support Works
Tony McLean	Manager	Access Ability Taranaki
Karen Mora	Team Leader	Options, Hawkes Bay
Jane Pembroke	National NASC Manager	LIFE Unlimited Charitable Trust
Anne Simpson	Manager	Life Links
Don Sorrrenson	Regional Manager	Support Net Kupenga Hao Ite Ora

Appendix 4: Self-assessment stock-take interview questions

1. - What does self-assessment mean to you in the context of your work?

2. - What do you see as the purpose of self-assessment?

3. - Under what conditions, and for whom, do you think self-assessment is most appropriate?

4. - What do you think are the key domains for a self-assessment to enable service coordination

5. - Do you use, or are you aware of any examples of self-assessment tools or practices?

6. - If you currently use self-assessment tools or practices, please describe:
    i. Their purpose
    ii. The client group(s) they are used with
    iii. - How they were developed (e.g. in-house or adapted from elsewhere))
    iv. - When and how they were implemented
    v. The impact of the tools/processes on staff, clients and processes.

7. - Are there any other comments or information you would like to add?

CHALLENGING SEGREGATION AS ‘CHOICE’

Sometimes it is argued that persons with disability ‘choose’ to live in segregated accommodation options, and that Governments must give effect to this ‘choice’ on the basis that the right to personal autonomy overrides all other values. The real facts underlying these situations very rarely reflect such claims.

In most situations of this type, persons with disability have been, or continue to be, obliged to live in segregated environments in order to receive essential support services. Governments could just as readily provide these support services in the community, and indeed, as we have noted, Article 19 of the CRPD makes it clear that they have a fundamental obligation to do so.

In other situations, this will have historically been the case, and the individuals concerned may have become institutionalised by many years of segregated living. Institutionalisation is the outcome of systematic subordination of a person to inflexible external social, medical or legal controls. It results in the suppression and degradation of autonomy and personality, and is, in fact, the ultimate opposite of personal autonomy. This life experience makes it difficult for the person to imagine or trust in the promise of a positive community based alternative. However, institutionalisation of the person can be overcome through sensitive structured engagement of the person in normative patterns of life.

In most other cases it is not persons with disability who are making this ‘choice’ at all. It is family members, carers, guardians, service providers, and policy makers who seek to persist with, or impose, segregated housing and support options on persons with disability.

In many cases family members have come to rely upon institutional settings because they were initially advised by health professionals and service providers that this was the only option possible for their family member with disability. The decision to place the person in an institutional setting may have been a very painful one which it is difficult to revisit, particularly where this must involve some level of recognition and acceptance of the harm that institutionalisation has caused their relative. In some cases, family members may feel personally blamed for this harm, or experience feelings of guilt about their original decision. This may make community based living options – and the human rights related premises on which they are based – difficult to accept. This calls for a high degree of sensitivity and skill in the positive engagement of family members in planning for community based living for their relative. The vast majority of family members, including those who have expressed vigorous opposition to community living, strongly support community based alternatives once they and their relative with disability have experience of them.

Often the language of choice masks other, far less palatable, motivations. In reality, the real motivator may be a view of persons with disability as socially inferior, and therefore as not entitled, or not capable, of living an ordinary life in the community. The real aim may be to prevent persons with disability from causing social discomfort to others (including their own family members, neighbours, and the community generally).

Service providers and policy makers may view segregated institutional models of care as a ‘cheaper’ social support option for Government (although in most cases institutional models of support are, in fact, more expensive than community based models). Family members, carers and guardians may view segregated institutions as ‘safer’ places for persons with disability to live, even though the evidence overwhelmingly demonstrates that they are associated with very high rates of neglect, violence and abuse of persons with disability.

Whatever the cause or motivation, the suppression of autonomy and personality of the individual by segregated, institutional models of housing and support is offensive to human dignity.

As we have already noted, human dignity is the ultimate source of all human rights, and it might also be conceptualised as the end goal of all human rights. Consequently, all human rights must be interpreted and applied in a way that respects, protects and fulfils human dignity.[xivxv] Human dignity has both a personal and collective dimension; that is, it encapsulates, and insists upon, fundamental values for the individual and for societies as a whole.[xvi] It is therefore an obligation that applies to duty bearers (those who must respect, protect and fulfil human rights) as much as it does to right bearers (those whose rights must be respected, protected and fulfilled). In other words, right bearers as well as duty bearers have a fundamental responsibility to act in ways that respect, protect and fulfil human dignity. This has important implications for resolving the clash of constituent or subordinate human right values.

Even in those very rare situations where persons with disability seek segregated housing and support options, it means that Governments are under a clear obligation to protect and preserve human dignity. To do otherwise would degrade the dignity of all persons with disability, and our society as a whole, by creating or preserving social institutions that perpetuate a belief in the social inferiority of persons with disability.

The patterns of behaviour and belief associated with segregated housing models may create delicate and painful challenges to be resolved. But experience overwhelmingly demonstrates that they can be resolved with startling benefits not only for persons with disability, but for all stakeholders, and the community as a whole.

Attitudes and beliefs that perpetuate segregated housing options for persons with disability must be challenged and overcome. In this respect Article 8 of the CRPD makes the human rights obligations of parties very clear. They must 'adopt immediate, effective and appropriate measures:'

- To raise awareness throughout society, including at the family level, of the rights of persons with disability, and to foster respect for the rights and dignity of persons with disability;
- To combat stereotypes, prejudices and harmful practices relating to persons with disability in all areas of life; and
- To promote awareness of the capabilities and contributions of persons with disability.

Governments therefore fail to respect, protect and fulfil human rights if they acquiesce in, or seek to take advantage for their own purposes, of calls for the establishment or perpetuation of segregated housing and support options for persons with disability.

CHALLENGING CONGREGATION AS 'TYPICAL'

It is also sometimes argued that housing and housing and support options that congregate persons with disability together in significant numbers are justifiable because other people in the community choose to live this way. The most often cited example of 'typical' congregate accommodation options are residential services for older and elderly persons.

This argument ignores or distorts very important facts.

First, as we have already noted, the CRPD provides a very specific human rights related prohibition on the delivery of housing and housing and support services in ways that result in the segregation of persons with disability from their non-disabled peers and in the isolation from the community. The CRPD is clear that arrangements of this nature are human rights violations. All Australian Governments have a solemn obligation to recognise, respect, protect and fulfil CRPD rights. It is therefore not open to Governments to act in violation of these rights no matter what conditions may prevail with respect to other population groups within the community.

Second, the claim that older and elderly persons ‘prefer’ to live in institutional accommodation services is seriously misstated. In fact, in many cases, older and elderly persons are obliged or compelled to live in these environments in the same way that persons with disability have been historically. These environments have all of the same problems that institutional environments for persons with disability have had, and continue to have. If the necessary supports were provided that would enable older and elderly persons to age in their own homes safely and with dignity, the vast majority would do so. To a significant extent aged care policy now recognises this in its emphasis on the development and delivery of supports that will allow older people to ‘age in place;’ that is, in their own homes and communities, rather than in specialist aged care facilities.

Third, the ‘contemporary’ institutional housing and support options that are advanced on this premise are actually segregated simulations of the larger group style accommodation they take as their precedents. Subject to other human rights considerations being satisfied, if persons with disability were to choose to live in larger group environments with a range of other persons of their choice, there may be no objection to such arrangements. However, that is not what the proposed ‘contemporary’ institutional models of accommodation involve. They segregate persons with disability from their non-disabled peers. In those circumstances where these facilities simulate services for older and elderly persons, they also typically violate age-related norms. Non-disabled ‘younger’ adults do not choose to live in residential aged care facilities.

Finally, it might be observed that there is a significant qualitative difference between a frail elderly person nearing the end of their life being accommodated in a residential facility, and a young person with disability with many years of life to lead being accommodated in such a facility. Such accommodation is not preferable for either group but it is more intensely inappropriate for younger persons with disability.

The Senate

Standing Committee on Community Affairs

Aged Care Amendment (Security and Protection) Bill 2007 [Provisions]

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THE INQUIRY

1.1 The Aged Care Amendment (Security and Protection) Bill 2007 was introduced into the House of Representatives on 8 February 2007, passed the House on 15 February and was introduced into the Senate on 26 February 2007. On 8 February 2007, the Senate, on the recommendation of the Selection of Bills Committee (Report No. 2 of 2007), referred the Bill to the Community Affairs Committee (the Committee) for report.

1.2 The Committee received 15 submissions relating to the Bill and these are listed at Appendix 1. The Committee considered the Bill at a public hearing in Canberra on 1 March 2007. Details of the public hearing are referred to in Appendix 2. The submissions and Hansard transcript of evidence may be accessed through the Committee's website at http://www.aph.gov.au/senate_ca .

THE BILL

1.3 The purpose of the Bill is to amend the *Aged Care Act 1997* to provide new measures to protect aged care residents, including:

- a regime for compulsory reporting of physical and sexual assaults of people in aged care;
- protections for approved providers and staff who report assaults of people in aged care;
- establishment of complaints investigation arrangements through new Investigation Principles; and
- establishment of the Aged Care Commissioner to replace the existing Commissioner of Complaints.

Compulsory reporting

1.4 In the Bill a 'reportable assault' is unlawful sexual contact, unreasonable use of force, or assault specified in the Accountability Principles and constituting an offence against a law of the Commonwealth or a State or Territory that is inflicted on a person receiving Commonwealth funded residential aged care services. If an approved provider receives an allegation of, or starts to suspect on reasonable grounds, a reportable assault, the approved provider is responsible for reporting the allegation or suspicion as soon as reasonably practicable and in any case within 24 hours. The report must be made to a relevant police officer and to the Secretary.

1.5 The proposed provisions outline an exception to this responsibility on approved providers in the circumstances (if any) specified in the Accountability Principles. The Department of Health and Ageing's Explanatory Guide to the Bill states that this exception 'is intended to deal with very specific and sensitive circumstances – such as assaults carried out by residents with a mental impairment'.[1]

1.6 The proposed amendments define 'staff member' as an individual who is employed, hired, retained or contracted by the approved provider (whether directly or through an employment or recruiting agency) to provide care or other services. Approved providers are responsible for taking reasonable measures to require each of their staff members, who suspects on reasonable grounds that a reportable assault has occurred, report the suspicion as soon as reasonably practicable to one or more of the following: the approved provider; one of approved the provider's key personnel; another person authorised by the provider to receive reports of suspected reportable assaults; a police officer; or the Secretary.

Protections for those who report

1.7 A disclosure of information by a person qualifies for protection under proposed sub-section 96-8(1) if:

- the discloser is an approved provider or a staff member of an approved provider;
- the disclosure is made to: a police officer, the Secretary, the approved provider, one of the approved provider's key personnel or another person authorised by the provider to receive reports of alleged or suspected reportable assaults; and
- the discloser reveals their name and the disclosure is made in good faith.

1.8 If a person makes a protected disclosure they are not subject to any civil or criminal liability for making the disclosure and no contractual or other remedy may be enforced against the person on the basis of the disclosure. The person making a protected disclosure has qualified privilege in proceedings for defamation and is not liable to an action for defamation relating to the disclosure. A contract to which the person is party may not be terminated on the basis that the disclosure constitutes a breach of contract.

1.9 If a court is satisfied that a person has made a protected disclosure and that person's contract of employment has been terminated on the basis of the disclosure, the court may order that the person be reinstated or paid an amount by the employer.

1.10 A person must not cause detriment (by act or omission) to, or make a threat (whether express or implied or conditional or unconditional) to cause any detriment to, another person because they have made a protected disclosure.

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[1] *Submission* 13, Attachment A, p.6 (Department of Health and Ageing).

1.11 Approved providers are also responsible for ensuring, as far as reasonably practicable, the protection of staff members who make a protected disclosure. In particular the approved provider must ensure, as far as reasonably practicable:

- that any staff member who makes a disclosure does not have contractual or other remedies enforced or exercised against them, because they made a protected disclosure;
- that any contract with a staff member who makes a protected disclosure is not terminated on the grounds that the staff member made the protected disclosure;
- that any staff member who makes a protected disclosure does not suffer a detriment because they made a protected disclosure; and
- that any staff member who makes a protected disclosure does not suffer a threat because they made a protected disclosure.

1.12 This covers not only compliance by the approved provider itself but extends to the ensuring as far as reasonably practicable that there is also compliance by others, such as other staff members of the approved provider and other parties with whom the approved provider contracts (for example an employment agency).

1.13 If a person reports a suspected reportable assault to the approved provider, the provider is responsible for taking reasonable measures to ensure that the fact that the person was the maker of the report is not disclosed, except to police, the Secretary, the approved provider's key personnel or when required by law.

Investigation Principles

1.14 The Investigation Principles (to be made by the Minister) may make provision relating to the investigation of matters (including complaints) relating to the Act or the Principles including: which matters are investigated; how investigations are to be conducted; considerations in making decisions relating to investigations; and procedures for reconsideration or examination of decisions in relation to investigations.

1.15 The Investigation Principles may make provision relating to actions which must be taken if it is found in an investigation that an approved provider has not complied with its responsibilities.

The Aged Care Commissioner

1.16 The new role of Aged Care Commissioner has a number of functions, including:

- to examine certain decisions made by the Secretary under the Investigation Principles and make recommendations to the Secretary arising from examinations;

- to examine complaints made to the Aged Care Commissioner about the Secretary's processes for handling matters under the Investigation Principles and make recommendations arising from examinations;
- to examine complaints made to the Aged Care Commissioner about the conduction of an accreditation body (currently the Aged Care Standards and Accreditation Agency) relating to its responsibilities under the Accreditation Grant Principles; or the conduct of a person carrying out an audit, or making a support contact under those principles. Examinations of conduct may also be initiated by the Aged Care Commissioner. The functions of the Aged Care Commissioner expressly exclude examination about the merits of a decision;
- to advise the Minister, at the Minister's request, about matters relating to any of the Aged Care Commissioner's functions; and
- other functions (if any) specified in the Investigation Principles.

BACKGROUND

1.17 On 27 July 2006 the Minister for Ageing, Senator the Hon Santo Santoro announced a $90.2 million package of reforms to take effect from 1 April 2007 aimed at further safeguarding residents in aged care homes from sexual and serious physical assault.[2] This followed an earlier announcement of compulsory police background checks for aged care staff and volunteers and an increase in random unannounced inspections of aged care homes. These measures formed part of the Government's response to incidents which came to light in 2006 involving the alleged serious assaults and mistreatment of people in residential aged care.

1.18 The Minister for Ageing and the Department of Health and Ageing undertook consultation in the development of Bill, in part through the Minister's Aged Care Advisory Committee which met four times in 2006. The Minister also invited members of the public, including care recipients and their families, to write to him through the Residential Aged Care Taskforce established in February 2006.[3]

1.19 The Aged Care Amendment (Security and Protection) Bill 2007 was introduced into the House of Representatives on 8 February 2007 with a commencement date of 1 April 2007.

ISSUES

1.20 Amongst the submissions which the Committee received there was broad support for the reforms in the Bill to increase protections for elderly people in residential care from physical and sexual assaults. However, a number of significant issues of concern were also raised.

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[2] Minister for Ageing, Senator the Hon Santo Santoro, *Howard Government delivers major new safeguards against abuse*, Media Release SS68/06, 27 July 2006.

[3] *Submission* 13, p.4 (Department of Health and Ageing).

Commencement

1.21 The Bill provides that the new procedures commence on 1 April 2007 as was the intention when the Minister announced the reforms in July 2006. As the explanatory memorandum states 'this means that approved providers will be expected to start complying with the new responsibilities imposed by this legislation (including new responsibilities to compulsorily report certain assaults) from 1 April 2007'. The Explanatory Guide outlines the requirements for providers:

> From 1 April 2007, the approved provider must also have in place systems to alert staff to the reporting requirements. The approved provider must also have systems in place to protect the identity of staff that make disclosures and also to protect such staff from victimisation.[4]

1.22 Provider and staff representatives claimed that with the Bill still before Parliament and the Principles containing all the operational detail not to be finalised before the Bill has passed, it was not feasible to have all these new systems in place by the 1 April commencement date. They argued that to develop materials for and organise training so that staff can be appraised of and actually trained in their new responsibilities required a longer timeframe. Some proposed a delay of eight weeks to enable full and thorough implementation of the new arrangements.[5]

Investigation Principles

1.23 The amendments proposed in the Bill set the general framework for the reforms. Much of the operational detail about the practices and processes that will give effect to the reforms will be included in subordinate legislation, Aged Care Principles made under the Aged Care Act 1997. Proposed Division 94A provides for Investigation Principles that will detail the processes and procedures for complaint handling and investigation. However, while the Department has advised that the Principles cannot be finalised until the Bill has passed it has prepared an Explanatory Guide 'setting out the proposed content of the Principles in order to provide stakeholders with information about the totality of the proposed arrangements'. The Department has undertaken 'to consult on the content of the proposed Principles as they are developed and welcomes input from stakeholders'.[6]

1.24 The Principles are fundamental to the operation of the new measures dealing as they do with issues including the matters to be investigated and how investigations are to be conducted. A number of groups could only provide general comment without access to draft Principles. As the Elder Rights Advocacy commented:

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[4] *Submission* 13, Attachment A, p.9 (Department of Health and Ageing).

[5] *Committee Hansard* 1.3.07, p.14 (Australian Unity); p.17 (LHMU); p.21 (Aged and Community Services Australia and Aged Care Association Australia). Also *Submission* 10, p.3 (Aged Care Association Australia).

[6] *Submission* 13, pp.2-3 (Department of Health and Ageing).

> Overall we believe that the measures are good. We have a problem, though, in that we have not seen the principles…We would like to see the rest of the detail—the devil is always in the detail. We hope it is not; we hope that some of the measures that people are suggesting can be included in the principles to make this very workable.[7]

1.25 The Committee received a number of suggestions about what should be included in the Principles and how the procedures they provide should operate, including what would trigger an investigation, managing vexatious complaints, anonymous complaints, training requirements for staff, level and form of evidence, procedural fairness and appeal processes.[8]

1.26 A number of submissions highlighted the need to ensure that principles of natural justice and administrative fairness were reflected in the Investigation Principles and investigation procedures. The COTA over 50s Alliance commented:

> The amendments, along with the Investigation Principles, must ensure that, whilst they provide the appropriate mechanisms to achieve thorough and comprehensive investigations of reportable assaults, at all times natural justice is afforded all relevant parties. By the very nature of these offences, often presented as allegations and suspicions, there needs to be ample opportunities for all relevant parties to be able to answer or provide further explanations without fear of reprisal.[9]

1.27 Catholic Health Australia noted there was 'no provision for a complainant to be informed of the Commissioner's recommendations or have recourse should the complainant be dissatisfied with these recommendations.'[10] Similarly Aged and Community Services Australia commented:

> The Bill does not adequately address the issue of informing both the complainant and the party complained about on the outcomes of an investigation. The legislation should specify that both parties are informed of the outcomes of an investigation.[11]

1.28 The Department gave a commitment that 'all relevant parties, including approved providers, will be afforded natural justice and procedural fairness during the course of investigations (and this will be expressly provided for in the Principles)'. [12]

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[7] *Committee Hansard* 1.3.07, p.2 (Elder Rights Advocacy). Also *Submission* 12, p.3 (Health Services Union).

[8] *Submission* 8, pp.2-3 (Elder Rights Advocacy); *Submission* 9, pp.1-2 (Aged and Community Services Australia); *Submission* 5, p.1 (Liquor Hospitality and Miscellaneous Union).

[9] *Submission* 3, p.2 (COTA over 50s Alliance).

[10] *Submission* 6, p.5 (Catholic Health Australia).

[11] *Submission* 9, p.2 (Aged and Community Services Australia).

[12] *Submission* 13, Additional information dated 7.3.07, p.9 (Department of Health and Ageing).

1.29 The Committee expects that all these issues relating to the Principles will be considered during the process being undertaken by the Department in the development of the Principles. The Committee does note that consultation drafts of the Private Health Insurance Rules were available for public comment while the Private Health Insurance Bill 2006 was progressing through Parliament and that this assisted in an understanding of many aspects of that Bill.

Compulsory reporting

Scope

1.30 Under the provisions of the Bill if an approved provider receives an allegation or starts to suspect on reasonable grounds a reportable assault the approved provider is responsible for reporting to the relevant police force and the Department of Health and Ageing. There were significant concerns expressed to the Committee about the details of the operation and scope of the compulsory reporting requirements, particularly the requirement to report to police. The undesirability of reporting resident-on-resident and resident-on-staff assault was a common theme among submissions. There was much commentary on the practicality of a system of otherwise compulsory reporting and a number of possible alternatives to the proposed model were proffered.

1.31 Aged and Community Services Australia noted that 'an allegation must be reported whether it is based on reasonable grounds or not, but suspicions have to be on reasonable grounds…wouldn't the same test of reasonableness apply to both allegations and suspicions?'.[13] Australian Unity argued for a higher threshold before approved providers were required to report allegations or suspicions:

> Section 63-1AA (2) states
>
> "If the approved provider receives an allegation of, or starts to suspect on reasonable grounds etc…"
>
> Our recommendation is that the word 'or' should be replaced with 'and' so that aged care providers may assess the situation and establish that on reasonable grounds a particular incident is a case of suspected abuse.[14]

1.32 Australian Unity fully supported mandatory recording of all allegations, even when there were no reasonable grounds to suspect a reportable assault. They also noted that requiring reasonable grounds before requiring reporting would limit the number of mistaken or vexatious claims.[15]

1.33 In evidence Australian Unity offered an alternative position. In some cases, it was suggested, police involvement is unnecessary. Excessive police involvement would over-burden the system. It argued that care-providers should report only where

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[13] *Committee Hansard* 1.3.07, p.20 (Aged and Community Services Australia).

[14] *Submission* 7, p.3 (Australian Unity).

[15] *Committee Hansard* 1.3.07, p.11 (Australian Unity).

there were 'reasonable grounds to suspect…assault'. They felt a parallel set of obligations, one based on reasonable reporting, and one based on the mandatory recording of all incidents, would be sufficient. All records could be reviewed by the Department of Health and Ageing at their convenience. Family members, dissatisfied with the actions of health-providers, could demand that incidents be reported.[16]

1.34 The Australian Medical Association argued that the scope of the compulsory reporting responsibilities was too broad and should be focused on the abuse of elderly residents by staff. They commented:

> The AMA has maintained that while abuse between residents needs to be addressed, extending the focus of compulsory reporting to resident-on-resident and resident-on-staff interactions is inappropriate, and will have significant resource implications. The AMA strongly believes that the core focus of compulsory reporting should be on preventing elder abuse by health care workers.[17]

1.35 During the hearing the issue was raised that the compulsory reporting measures in the Bill could lead to police and Department resources being diluted or diverted, so that serious cases of abuse by staff members or others were not adequately investigated. Dr Ford of the Australian Medical Association stated that resident on resident assaults in aged care facilities were very common:

> If the staff or the providers take a defensive approach to this and basically see that they cannot define it and will report everything, then it could become unworkable and the element that we wish to really pursue would fail to be addressed.[18]

1.36 However the Department commented that in developing the legislation a blanket exemption for all aged care residents did not seem defensible.

> There are 170,000 people every night in residential aged care. They consist of a complete slice of the human community in Australia. There are people there that have been in the past perpetrators of very serious crimes. There are people there who are bullies. There are people there who are predators. There have been also, in the past, for people who have worked in aged care for a long time, some really very grievous examples of resident-on-resident abuse.[19]

1.37 There was concern that the language of the Bill in relation to compulsory reporting requirements for approved providers and staff members lacked clarity. Aged and Community Services Australia noted that:

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[16] *Committee Hansard* 1.3.07, pp.9,10,13 (Australian Unity).

[17] *Submission* 14, p.1 (Australian Medical Association).

[18] *Committee Hansard* 1.3.07, p.30 (Australian Medical Association).

[19] *Committee Hansard* 1.3.07, pp.36-37 (Department of Health and Ageing).

> The use of terms "unreasonable" and "start to suspect" are vague and open to interpretation. A tighter definition of these terms is required. Providers should not be required to report on the basis of suspicion - this is likely to waste time and resources of both the providers and the police forces.[20]

1.38 Australian Unity sought 'clarification on the obligations of other health professionals involved with our residents, such as GPs and allied health professionals in advising us as the approved provider of a suspected abuse'.[21] The Department noted that:

> There are existing mechanisms in place which encourage health professionals to report abuse. The Aged Care Act currently requires approved providers to comply with relevant state and territory laws…
>
> Regardless of any legislative requirements to report, it is important to note that:
>
> - any person (including health professionals) may at anytime make a report to the Department and this will be investigated;
> - the Department (including through approved providers) encourages any reporting of abuse or other issues of concern regarding the treatment and safety of residents;
> - the Department’s communications strategy for the new arrangements will target GPs and hospitals; and
> - approved providers can also encourage health professionals to report any abuse to the approved provider (who plays a crucial role in relation to the care and safety of residents) or to the police or Department. [22]

Compulsory reporting and police

1.39 A number of submissions and witnesses stressed the need for sensitivity in investigating assaults in residential aged care facilities. Australian Unity noted:

> Where police are required to investigate, we believe that community policing squads or sexual assault units are the most appropriate police to intervene in these cases…Consideration of the gender of the investigating police officer will also be paramount to the victim and their family.[23]

1.40 Aged and Community Services Australia also noted that the definition of 'reportable assault' in the Bill may require approved providers to report non-criminal conduct to police.

> The phrase "unreasonable use of force" encompasses criminal and non-criminal conduct. Given the reference to unlawful sexual contact and an

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[20] *Submission* 9, p.3 (Aged and Community Services Australia).

[21] *Submission* 7, p.4 (Australian Unity).

[22] *Submission* 13, Additional information dated 7.3.07, p.5 (Department of Health and Ageing).

[23] *Submission* 7, p.4 (Australian Unity).

> assault, it is unclear what this is referring to. To the extent that it covers non-criminal conduct, it seems inappropriate to require such a report to the police.[24]

1.41 The Department advised that:

> The guidelines to the industry will make it clear that if an approved provider is in any doubt as to whether unreasonable force has been used, the approved provider should err on the side of reporting to police and the Department. Approved providers are currently making similar assessments when they decide whether or not to report incidents to the Department or the police under existing voluntary reporting arrangements.
>
> While each case will be judged on its merits, an example of reasonable use of force in the context of compulsory reporting of assaults would be where a staff member is genuinely trying to assist a care recipient, but despite their best intentions the care recipient is accidentally injured.
>
> An example of unreasonable use of force would be where a staff member is violent towards a resident.[25]

1.42 The Committee is concerned that with the new reporting arrangements to commence on 1 April, the level of consultation undertaken with Commonwealth, State and Territory police forces in developing the terms of the Bill, and particularly in developing procedures to respond to the additional burdens compulsory reporting might put on police resources, has been inadequate. This was especially the case as the Department indicated there was no available data to even indicate approximately how many incidents would be reported to police as a result of the legislation.

1.43 The Department advised that members of the Australian Federal Police had attended meetings of the Aged Care Advisory Committee when the issue of compulsory reporting was being explored. While the Department's State and Territory offices have been meeting with relevant police forces, since January 2007 meetings have only been held in the ACT, Queensland and Victoria to discuss police check requirements and the issue of compulsory reporting. Meetings with other States are being arranged.[26]

1.44 As noted earlier, compulsory reporting has a dual reporting requirement – to the police and to the Department. The Department explained the purpose of this requirement:

> The purpose of the police involvement is to assess whether criminal activity has occurred and if charges need to be laid. The police are the best and most appropriate authorities to make that judgement. The purpose of reporting to

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[24] *Submission* 9, Additional information 2.3.07, p.1 (Aged and Community Services Australia).

[25] *Submission* 13, Additional information dated 7.3.07, p.3 (Department of Health and Ageing).

[26] *Submission* 13, Additional information dated 7.3.07, p.13 (Department of Health and Ageing).

> the department is for us to consider whether the approved provider has actually met its responsibilities under the aged-care legislation.[27]

While the Investigation Principles will outline how the Department, through the new Office of Aged Care Quality and Compliance, should conduct investigations, the investigation procedures to be adopted by police in assessing whether criminal activity has occurred will continue to be determined by the relevant State/Territory police service.

The right not to report

1.45 A number of submissions expressed concerns about whether the Bill would respect a competent person's right not to have an assault disclosed or reported to police or others. Australian Unity commented:

> An aged care facility is the resident's home and we believe, where appropriate, victims should have a choice as to the level of disclosure of their situation to the wider community within their aged care facility, and that any intervention by officials, either police or departmental, must be respectful of the victim's right to privacy.[28]

1.46 Aged and Community Services Australia considered that without such an option 'we [would be] giving older people fewer rights than we would to anyone else, simply because they are residents in residential care'.[29] Similarly the Australian and New Zealand Society for Geriatric Medicine argued that 'Young rape victims have the option of treatment without police intervention. Cognitively intact elderly residents should be accorded the same right.'[30]

1.47 Aged and Community Services Australia expressed concern that aged care providers would be forced to act against the wishes of residents:

> ACSA is concerned that the introduction of compulsory reporting takes away the rights of competent older people to determine whether or not they wish to take any action on an assault. Under the provisions of this Bill, approved providers are required to make reports in the absence of the alleged victim’s consent and even in the face of their refusal to grant such consent.[31]

1.48 However during the hearing it was also noted that while the Bill required approved providers to report reportable assaults to the police, the individual could still decide their level of cooperation with the investigation. The Department indicated that

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[27] *Committee Hansard* 1.3.07, p.37 (Department of Health and Ageing).

[28] *Submission* 7, p 3 (Australian Unity).

[29] *Committee Hansard* 1.3.07, p.19 (Aged and Community Services Australia).

[30] *Submission* 1, p.2 (Australian and New Zealand Society for Geriatric Medicine).

[31] *Submission* 9, p.2 (Aged and Community Services Australia).

if residents 'do not want the police to continue investigation or they do not want charges to be laid, they can have that discussion with the police.'[32]

1.49 The AMA argued strongly that the nature of the relationship between a resident and their provider mandated that there not be a discretion for the former not to report an assault:

> This is not an issue for that person alone. That is an indication of risk to everybody else in that residential care service and anywhere else that that casual worker might be working. The other thing I would have to say is that residents are sometimes frightened in that environment. They fear being thrown out. They fear not receiving the services. If you cannot walk and you are dependent on the people around you to stand you up so that you are not wet that day, it is very tough. I think that, irrespective of that, it will have to be worked through with the resident. Even if they have cognitive impairment, you would have to work through it with them, because it still has to be addressed. I do not think you can allow a situation where there has been a clear episode of abuse and the resident says, ‘Don’t take it any further,’ because the alleged perpetrator of that abuse is a risk for everybody else in the residential care centre.[33]

1.50 The Department commented on the tension between compulsory reporting requirements and the responsibility to respect residents' wishes not to have the matter reported:

> In the context of residential aged care, approved providers (and the Government) have an obligation not only to protect the victims of abuse (and, as far possible, to respect their wishes) but also to protect others in the residential aged care service and ensure the safety of all.
>
> Recognising the broader need to ensure the safety of others, the legislation adopts a cautious approach by requiring reporting of all allegations to police and the Department regardless of whether a resident agrees that such reporting should occur.
>
> While this may sometimes mean that the wishes of a particular resident may not be met, it also ensures that:
>
> - the safety of all residents is paramount; and
> - there can be no pressure on a resident to encourage them not to report because the approved provider will be required to report.[34]

Discretion not to report

1.51 The Explanatory Guide to the Bill provides for a discretion for approved providers not to report assaults in recognition that 'assaults by residents with mental

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[32] *Committee Hansard* 1.3.07, p.41 (Department of Health and Ageing).

[33] *Committee Hansard* 1.3.07, p.33 (Australian Medical Association).

[34] *Submission* 13, Additional information dated 7.3.07, p.6 (Department of Health and Ageing).

impairments are not uncommon, and in such cases, the focus should be on behaviour management of the resident with the mental impairment and protection of residents, and not police involvement, which can be traumatic for all involved.' The Guide states:

> [I]t is proposed that the *Accountability Principles 1998* would provide approved providers with the discretion not to report a reportable assault to the police and the Office if the following three circumstances all exist:
>
> - the approved provider must have reasonable grounds for believing that the person who carried out the reportable assault is a resident. The approved provider must form this view within the 24 hours after the allegation of the reportable assault or after starting to suspect on reasonable grounds that a reportable assault has occurred;
> - a medical diagnosis of mental impairment must have been made in respect of the resident and documentation must exist showing that the resident is mentally impaired. Both the diagnosis and the documentation must exist prior to the allegation of the reportable assault or the approved provider starting to suspect on reasonable grounds that the reportable assault occurred. If this is not the case, then a report must be made to the police and the Office, within 24 hours of the allegation or suspicion; and
> - the approved provider has a behaviour management plan in relation to the particular resident who is suspected to have carried out the assault.
>
> It is also proposed that section 19.5 of the Records Principles 1997 be amended to require that the approved provider keeps a record of all such incidents where assaults are not reported because of reliance on these alternative requirements.[35]

1.52 The importance of the discretion for aged providers outlined in the Explanatory Guide was highlighted in evidence to the Committee indicating the high proportion of aged care residents with dementia or cognitive impairment. The Australian and New Zealand Society for Geriatric Medicine indicated that 'Dementia and cognitive impairment are very common conditions in residents of nursing homes (at least 50%) and hostels (at least 30%)', while the Australian Medical Association suggested that up to 60% of residents in low care and 80% in high care could have some form of cognitive impairment.[36] The AMA also noted the difficulties in the accurate diagnosis of dementia or mental impairment and the currency of a formal diagnosis (which is required in accordance with the procedure outlined in the Explanatory Guide):

> While a diagnosis of cognitive impairment often occurs upon admission to an aged care facility, this process is not always formalised at this stage, the

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[35] *Submission* 13, Attachment A, pp.6-7 (Department of Health and Ageing).

[36] *Submission* 1, p.1 (Australian and New Zealand Society for Geriatric Medicine); *Submission* 14, p.1 (Australian Medical Association).

> diagnosis does not always remain current, and the current cognitive status of a previously competent resident might not be known.[37]

1.53 During the hearing there were concerns expressed about who would make a diagnosis of mental impairment for residents and whether it was possible for up-to-date medical records to be maintained. The Department indicated it expected that residents would be seen by a medical professional on a regular basis to assess their needs. The Department also indicated that it expected that for the purposes of the Bill a diagnosis of mental impairment would be made by a general practitioner or a geriatrician.[38]

1.54 There was concern that the discretion in relation to assaults by aged residents with mental impairments would detract from approved providers' obligations to provide a safe environment for all aged care residents. The Aged Care Crisis Team noted:

> We see here no requirement of the provider to exercise 'duty of care'. A frail elderly person, powerless to defend him/herself is not afforded protection and has no recourse when the provider does not adequately manage the resident with dementia.[39]

Training and Awareness

1.55 Staff training and awareness of the compulsory reporting requirements in relation to abuse of people in aged care were identified as crucial to the success of the Bill.[40] The Liquor Hospitality and Miscellaneous Union submitted that the Bill should include guidelines for training requirements for staff that are obligated to report suspected assault under compulsory reporting. The Union noted that:

> A compulsory reporting system will do nothing to stop the incidence of abuse against elders if aged care staff members are not trained to detect symptoms of abuse, and contend with the difficult discussions with residents, providers, staff and families that could follow detection of abuse.[41]

Retrospective effect?

1.56 The Explanatory Guide to the Bill notes that, subject to the passage of the legislation, approved providers will be expected to comply with these new requirements from 1 April 2007. It continues:

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[37] *Submission* 14, p.1 (Australian Medical Association).

[38] *Committee Hansard* 1.3.07, p.35 (Department of Health and Ageing).

[39] *Submission* 11, p.3 (Aged Care Crisis Team).

[40] *Submission* 12, p.12 (Health Services Union).

[41] *Submission* 5, p.3 (Liquor Hospitality and Miscellaneous Union).

> From 1 April 2007, approved providers will have to report any reportable assaults that come to their attention.
>
> This includes assaults that may have occurred before 1 April 2007, but were not reported to the approved provider until after 1 April 2007.[42]

1.57 Several submissions raised the status of past allegations and suspicions in relation to reportable assaults and the possible retrospective effect of the Bill's provisions. Aged and Community Services Australia commented:

> Given that a reportable assault may take place before or after the commencement of the legislation, there is a potential for pre-1 April 2007 reportable assaults which have already been dealt with by an approved provider, to be the subject of an allegation or suspicion post-1 April automatically invoking the requirements under section 63-1AA(2).[43]

1.58 Mr Brian Herd also suggested that ' providers will now need to pour over their records (or memory) to determine what past or existing allegations were received or suspicions arose.'[44]

1.59 The Department commented:

> The bill requires that if an issue comes to the provider’s attention after 1 April, which is the proposed commencement date, then that must be reported… The incident may have occurred on 30 March and it comes to the provider’s attention on 1 April. Because the bill is imposing a reporting obligation, there is a reporting obligation on the provider once they become aware of the incident.[45]

Whistleblower protections

Scope of protections

1.60 Previously the Committee has recommended that the Commonwealth examine the feasibility of 'introducing whistleblower legislation to provide protection for people, especially staff of aged care facilities, disclosing allegations of inadequate standards of care or other deficiencies in aged care facilities'.[46] However the Health Services Union noted that the protections in the Bill are limited to physical and sexual assaults and do not provide protections for staff or others who make disclosures regarding other deficiencies in relation to the services provided to those in aged care.[47]

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[42] *Submission* 13, Attachment A, p.9 (Department of Health and Ageing).

[43] *Submission* 9, Additional information 2.3.07, p.1 (Aged and Community Services Australia).

[44] *Submission* 15, p.1 (Mr Brian Herd).

[45] *Committee Hansard* 1.3.07, p.36 (Department of Health and Ageing).

[46] Senate Community Affairs References Committee, *Quality and equity in aged care*, June 2005, p.65.

[47] *Submission* 12, p.6 (Health Services Union).

1.61 This point was also addressed by the Aged Care Crisis Team in its submission:

> Only a small minority of cases of elder abuse involve breaking the law; so the vast majority of cases do not come under compulsory reporting. Thus, most cases of physical abuse, all emotional abuse, financial abuse and incidents of neglect are not covered…Whistleblowers are only protected if they report reportable offences. So, again, the whistleblower will have no protection if he/she reports the vast majority of cases of elder abuse as outlined above.[48]

1.62 Aged and Community Services Australia noted that the protection provisions in section 96-8 'do not extend to non-staff members who may make a complaint, such as residents, family members or visitors.'[49] This issue was also highlighted by Elder Rights Advocacy who reported instances of aged care advocates and families of residents being threatened with legal action for pursuing complaints.[50]

1.63 Catholic Health Australia indicated the scope of the protection for whistleblowers was limited by the Bill's focus on the role and responsibilities of approved providers:

> Whilst a person may not make a threat or cause any detriment to another person, the only action that the Australian Government can take to enforce these provisions is with respect to approved providers. Where an individual staff member or a relative victimises a discloser, the Commonwealth would be powerless to act.[51]

1.64 The Aged Care Association Australia argued that employers should also be protected where they comply with their responsibilities.

> ACAA is concerned that though there are specific provisions that obliges employers to protect employees who report a reportable assault there appears little protection for employers who undertake their obligations under the legislation but are still potentially liable for unfair dismissal action, defamation and slander where action is taken in response to an allegation or suspicion which subsequently proves erroneous or false.[52]

1.65 In addressing this issue the Department argued that:

> Family members, residents, visitors and funded advocates are not required by the proposed provisions to report abuse and therefore they do not have statutory protection.

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[48] *Submission* 11, p.2 (Aged Care Crisis Team).

[49] *Submission* 9, Additional information 2.3.07, p.1 (Aged and Community Services Australia).

[50] *Committee Hansard* 1.3.07, pp.2-5 (Elder Rights Advocacy).

[51] *Submission* 6, p.6 (Catholic Health Australia).

[52] *Submission* 10, p.5 (Aged Care Association Australia).

> However, such people will be encouraged to report abuse and if they do so, they are able to report to the Department confidentially or anonymously (as they can currently).[53]

Responsibility of approved providers

1.66 Under the Bill approved providers are responsible to ensure staff members who make protected disclosers are not victimised. The Explanatory Guide noted that this responsibility 'covers not only compliance by the approved provider itself with the provision but extends to the approved provider ensuring as far as reasonably practicable that there is also compliance by others, such as other staff members of the approved provider and other parties with whom the approved provider contracts (for example, an employment agency)'.[54] However some doubted approved providers would be in a position to comply with this responsibility. Aged and Community Services Australia argued:

> It is difficult for a provider to be held responsible for the actions of a contractor once the contractor is off site or has completed their role. It is impossible for the provider to ensure protection once the person is no longer on site. The legislation should make the contractor responsible for the actions of their employees. The definition of a staff member needs to be narrowed to reflect this. A provider should not be held responsible for a third party.[55]

1.67 The Department advised that:

> …the legislation recognises that the approved provider cannot ultimately control the actions of individuals be they staff, external contractors or anyone else. This is why the legislation does not say that the approved provider must prevent any victimisation against a discloser (something for which the approved provider could not possibly exercise any control) but rather that the approved provider take reasonable measures to prevent victimisation – this could include, for example, limiting the number of people who are told the identity of the discloser and advising such people about responsibilities not to victimise.[56]

Protections for staff members

1.68 The Health Services Union proposed an amendment to the part of the Bill relating to reinstatement and compensation of staff members who have had their employment terminated because of a protected disclosure:

> The union is also concerned that there is very little detail in Section 96-8 (5) regarding how the clause would operate and apply and no assurance that

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[53] *Submission* 13, Additional information dated 7.3.07, p.8 (Department of Health and Ageing).

[54] *Submission* 13, Attachment A, p.8 (Department of Health and Ageing).

[55] *Submission* 9, p. 3 (Aged and Community Services Australia).

[56] *Submission* 13, Additional information dated 7.3.07, p.6 (Department of Health and Ageing).

> employees would be sufficiently compensated including all financial and other costs involved in the victimisation such as legal costs and compensation for pain and suffering where applicable. The clause currently provides for reinstatement **or** "an amount instead of reinstating the employee". This should be amended so that employees who are reinstated also have access to compensation.[57]

1.69 The Liquor Hospitality and Miscellaneous Union also submitted that the protections for staff members should be 'extended to protect whistleblowers who have their hours cut or established work tasks altered as a result of reporting suspected abuse'.[58]

1.70 The Committee has noted in paragraph 1.11 that under the Explanatory Guide an approved provider must ensure, as far as reasonably practicable, any staff member who makes a protected disclosure does not suffer a detriment because they made a protected disclosure.

1.71 The Department confirmed that:

> If a staff member has their hours cut or work tasks changed by the approved provider, solely on the basis of making a report, then the approved provider would be in breach of its responsibilities not to cause detriment to a discloser. Compliance action could be taken against the approved provider by the Secretary, under the Aged Care Act. [59]

Vexatious or mistaken allegations and suspicions

1.72 The Bill requires that a protected disclosure must be made in good faith. However there was considerable concern expressed about situations where vexatious or mistaken allegations and suspicions about reportable assaults could be made. The Australian and New Zealand Society for Geriatric Medicine commented:

> The staff of residential care facilities may have concerns about their rights if they are thought to be behaving inappropriately. There must be safe guards for staff against false or mistaken accusations. This will need to be balanced against the requirement for reporting. While this is incorporated in the bill, there may be considerable disruption to the operation of the residential care facility if each complaint is reported.[60]

1.73 The Aged Care Association Australia was also concerned that approved providers may be left with staff on special leave, at considerable cost, for protracted periods of time while a matter is investigated.[61]

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[57] *Submission* 12, p.5 (Health Services Union).

[58] *Submission* 5, p.4 (Liquor Hospitality and Miscellaneous Union).

[59] *Submission* 13, Additional information dated 7.3.07, p.8 (Department of Health and Ageing).

[60] *Submission* 1, p.2 (Australian and New Zealand Society for Geriatric Medicine).

[61] *Submission* 10, p.5 (Aged Care Association Australia).

Aged Care Commissioner

1.74 There was some criticism that the Aged Care Commissioner was not sufficiently separate from the Department of Health and Ageing to independently investigate complaints.[62] Elder Rights Advocacy noted that the 'perceived and actual independence and accountability of the Aged Care Commissioner's role in oversighting the scheme will be an important aspect of ensuring public confidence in the aged care system.'[63] Similarly the Liquor Hospitality and Miscellaneous Union commented that 'when the commissioner is internal to the Department, it seems that the perception of independence, for staff who are aware of the links between providers and the department, is what creates a lot of the difficulty around reporting'.[64]

1.75 Catholic Health Australia also noted that there was a risk that conflicts of interest could arise:

> The Commissioner may delegate all or any of his or her functions to an APS employee in the Department. This could result in the Department's own investigation officers from the Office of Quality and Compliance being asked by the Commissioner to examine matters handled by the Office.[65]

1.76 There were also some concerns about the limits on the Age Care Commissioner's functions. The Aged Care Association Australia commented:

> The Bill seems to confine the areas of possible investigation by the Commissioner to matters relating to the Investigation Principles and the Accreditation Grant Principles. ACAA believes that the Commissioner should be granted authority across all activities of the Aged Care Division, of the Department of Health and Ageing and not just the Investigation Principles and the Accreditation Grant Principles.[66]

1.77 The Aged Care Crisis Team noted that some limitations would make the Aged Care Commissioner less useful for complainants.

> The Aged Care Commissioner may only check that the Office for Aged Care Quality and Compliance and the Aged Care Standards and Accreditation Agency have followed the correct procedures; he/she is not permitted to deal with a complaint about the merits of a decision. For example, the Commissioner cannot indicate whether the investigation of a complaint resulted in a correct conclusion. A complainant, therefore, will have to go to the Administrative Appeals Tribunal (AAT), or even the Federal Court, for a full review of the complaint.[67]

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[62] *Submission* 5, p.4 (Liquor Hospitality and Miscellaneous Union).

[63] *Submission* 8, p.3 (Elder Right Advocacy).

[64] *Committee Hansard* 1.3.07, p.16 (Liquor Hospitality and Miscellaneous Union).

[65] *Submission* 6, p.5 (Catholic Health Australia).

[66] *Submission* 10, p.5 (Aged Care Association Australia).

[67] *Submission* 11, p.1 (Aged Care Crisis Team).

Other issues

Limits

1.78 A number of submissions pointed to the limits of the Bill in addressing all potential forms of abuse of people in aged care facilities. These included poor nutrition, hydration, hygiene, verbal and emotional abuse or financial fraud.[68] Australian Unity noted the scope of the protection in the Bill is limited to persons in Commonwealth funded aged care and noted that 'there are many older Australian who live in residential settings, such as Boarding Houses, Supported Residential Services in Victoria and Retirement Villages that could equally be at risk of abuse'.[69]

1.79 Staff training and staffing level were also raised as important factors in preventing elder abuse by some submissions. The Aged Care Lobby Group argued that the basic causes of abuse result 'from a pervading lack of properly trained and supervised staff in the majority of aged care facilities.'[70]

1.80 A number of submission and witnesses at the hearing were concerned the Bill did not clarify the position of aged care residents who have been accused or have been found to have committed a reportable assault. The Australia Medical Association called on the Government to 'consider what the fall back position might be for residents who are charged with assault in terms of the provision of appropriate care and accommodation thereafter.'[71] Aged and Community Services Australia noted:

> The legislation does not address what would happen to a resident accused of a reportable assault which is subsequently proven, and the resident may be convicted. This needs to be addressed in relation to the security of tenure provisions in the Aged Care Act.[72]

Sanctions

1.81 The new Office of Aged Care Quality and Compliance has responsibility for investigating information about possible non-compliance by approved providers under the Aged Care Act 1997. The Explanatory Guide notes that 'the Office will have the capacity to issue Notices of Required Action to providers who have breached their responsibilities, and take compliance action where the provider fails to remedy the issue'.[73] However Aged and Community Services Australia raised an issue regarding the legal status of the sanctions in the measures outlined in the Bill:

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[68] *Submission* 11, p.2 (Aged Care Crisis Team).

[69] *Submission* 7, p.2 (Australian Unity).

[70] *Submission* 2, p.1 (Aged Care Lobby Group).

[71] *Submission* 14, p.1 (Australian Medical Association).

[72] *Submission* 9, p.3 (Aged and Community Care Services Australia).

[73] *Submission* 13, Attachment A, p.13 (Department of Health and Ageing).

> In our opinion, the Department does not have the power to impose punitive sanctions or require compensatory payments. It seems to be contemplated that the Notice of Required Action may encompass a wide range of actions. Given that the AAT has in the past admonished the Department for imposing punitive sanctions, and we have seen in matters before the CRS settlements involving compensatory payments, this is a real concern.[74]

1.82 In relation to this issue the Department noted that:

> Notices of Required Action will require approved providers to address any breaches of their responsibilities under the Aged Care Act 1997 and to meet their responsibilities under that Act. If an approved provider does not comply with a Notice of Required Action then compliance action may be taken under the Aged Care Act – these are the same actions that can currently be taken by the Secretary for non-compliance with any of the approved provider's responsibilities.
>
> In the event that a breach of the approved provider's responsibilities relates to, for example, failure to repay a resident their full bond or over charging of a resident, then the Notice of Required Action could require the approve provider to repay the resident the appropriate amount – this is not a punitive penalty but rather seeks to restore the resident to the position they should have been in had they not been overcharged.[75]

Review of approach

1.83 The Department indicated there may be changes to the Principles to reflect the experience gained in implementing the measures in the Bill:

> I think an important reason for having these arrangements in the disallowable instrument is that we expect we are going to learn a great deal about this in the initial year or two. We are asking providers to keep registers of information and we are going to be asking the accreditation agency to make sure those registers are kept. I think we will all be a lot wiser in a year or two.[76]

1.84 The Health Services Union suggested that 'a comprehensive review of the changes occur in two years time to evaluate their effectiveness.'[77]

Financial Impact Statement

1.85 The Committee raised with the Department concerns at the lack of information contained in the explanatory memorandum's financial impact statement.[78]

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[74] *Submission* 9, Additional information 2.3.07, p.2 (Aged and Community Services Australia).

[75] *Submission* 13, Additional information dated 7.3.07, p.10 (Department of Health and Ageing).

[76] *Committee Hansard* 1.3.07, p.37 (Department of Health and Ageing).

[77] *Submission* 12, p.12 (Health Services Union).

[78] *Committee Hansard* 1.3.07, pp.41-42.

The explanatory memorandum simply states that 'the new initiatives that are implemented through this Bill are part of a $90.2 million (over four years) package of reforms aimed at further safeguarding older people in Australian Government-subsidised aged care from sexual and serious physical assault'.

1.86 The Department subsequently provided a more detailed breakdown of the $90.2 million divided over the 4 years by departmental, capital and administered (offset) expenditure. An indication of the areas of expected expenditure for 2006-07 and future years was also provided.[79] The Committee considers that at least this level of information should have been provided in the explanatory memorandum.

Conclusion and recommendations

1.87 The Committee supports the measures being introduced in the Aged Care Amendment (Security and Protection) Bill 2007. However, the Committee considers that there are a few areas that could be improved or refined and has recommended accordingly.

1.88 The Committee recognises the broad support for the Bill which contains urgent reforms with the important aim of protecting vulnerable people in aged care. However the Committee also acknowledges the legitimate concerns expressed in relation to the period of time it will take for approved providers to adequately inform and train staff members of the requirements of the Bill.

Recommendation 1

1.89 That in recognition of the additional responsibilities the Bill places on approved providers especially in relation to training staff members and instituting new systems, the commencement date, particularly in relation to the reporting provisions, be deferred for a period of at least one month.

1.90 The Committee has carefully listened to the issues which have been raised in relation to the compulsory reporting requirements for reportable assaults. There are obviously difficult questions regarding the appropriate treatment of resident-on-resident abuse and residents who may have mental impairments. The Committee also acknowledges the broad consultation which the Minister and the Department of Health and Ageing have undertaken in the development of the Bill. Nonetheless the Committee has concerns the Bill is being implemented when there is currently no clear evidence or reliable data as to the volume of reports which may result.

Recommendation 2

1.91 That the Department of Health and Ageing carefully and closely monitor developments in relation to the compulsory reporting regime upon its commencement and that care is taken to ensure the reporting mechanism operates as intended.

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[79] *Submission* 13, Additional information dated 7.3.07, p.12 (Department of Health and Ageing).

1.92 The Committee acknowledges that some concerns were raised that the implementation of the new measures may not fully achieve the desired goal of protecting vulnerable older people in residential care. The Committee notes that the Department has regular meetings with the Aged Care Advisory Committee and has undertaken to continue ongoing discussions with the sector in relation to the Principles and new measures after their introduction. The Committee considers that this process should provide appropriate opportunities for the sector to raise and have resolved any unforseen consequences arising from the implementation of the new measures. The Committee believes this process must be proactive and dynamic to address emerging issues of concern. The Committee leaves open the question of whether a more formal review of the legislation might be appropriate after, say, two years of operation.

1.93 As currently drafted the Bill only provides protections for approved providers and staff members who make protected disclosures. A number of submissions and witnesses to the inquiry suggested that some other persons should also be entitled to these protections where they make protected disclosures. The Committee agrees.

Recommendation 3

1.94 That the Bill be amended to extend the whistleblower protections to aged care residents, the families of residents and aged care advocates where they have reasonable grounds to suspect that the information indicates that a reportable assault has occurred and the disclosure is made in good faith.

Recommendation 4

1.95 That subject to the above recommendations, the Committee recommends that the Senate pass the Bill.

Senator Gary Humphries
Chairman

March 2007

ADDITIONAL COMMENTS BY LABOR SENATORS

While Labor Senators support the recommendations of the report, they do not agree that the whistleblower protections outlined in the Bill should be limited to only those who report the sexual or physical assault of residents of aged care. As noted in the Aged Care Crisis Team's submission, whistleblowers are 'only protected if they report reportable offences.' However there are many aspects to potential elder abuse which were highlighted in the Health Services Union submission:

> The legislative amendments before Parliament, though largely positive, are limited and do not address many aspects of abuse of older persons, particularly in regards to prevention.
>
> A guidance list on elder abuse issued by the Department of Health in the UK in 2000 identified six main forms of abuse: physical abuse, sexual abuse, psychological abuse, financial or material abuse, neglect and acts of omission and discriminatory abuse. Thus, abuse of older people has many different dimensions.

In the Quality and equity in aged care inquiry in 2005, the Committee recommended the 'Commonwealth examine the feasibility of introducing whistleblower legislation to provide protection for people, especially staff of aged care facilities, disclosing allegations of inadequate standards of care or other deficiencies in aged care facilities'. Labor Senators note that the Government has still not responded to this recommendation.

Labor Senators recommend that the whistleblower protections in the Bill be extended to include all forms of potential abuse of elderly people in residential aged care. This extension should include deficiencies in nutrition, hydration, hygiene, verbal and emotional abuse or financial fraud as well as any other instances of inadequate care.

It is in the interests of residents of aged care facilities and the broader Australian community for whistleblowers to be able to report not only reportable assaults but also to be able raise quality of care issues without fear of victimisation, reprisal and termination of employment.

Recommendation:

That the Bill be amended to afford whistleblower protection to people who report, on reasonable grounds, any form of abuse or neglect in residential aged care.

Senator Claire Moore ALP, Queensland	**Senator Carol Brown** ALP, Tasmania
Senator Helen Polley ALP, Tasmania	**Senator Jan McLucas** ALP, Queensland

Australian Democrats Additional Comments

Aged Care Amendment (Security and Protection) Bill 2007

The Australian Democrats welcome the committee's inquiry into the Aged Care Amendment (Security and Protection) Bill 2007. Given Australia's ageing population and the potential increases in the number of older people who may be vulnerable to abuse, it is timely that we consider the adequacy of responses to elder abuse.

The Democrats support efforts to ensure the safety of vulnerable older people and to provide ongoing protection from violence and abuse and consequently support the general tenor of the main Committee report and its recommendations.

However it is disappointing that the Government has failed to develop a consistent national policy framework to the prevention and alleviation of elder abuse in all its forms and locations. This will continue to be a major failing in effective responses to protecting senior Australians.

While the issues in relation to prevention, detection, intervention and response to elder abuse in community settings are different to those in residential aged care facilities, they warrant equal attention. Indeed given that the vast majority of perpetrators of elder abuse have been identified as family members, often living with the older person and doing so with Government support for them to remain at home, there is a risk of violence, abuse, neglect and exploitation that goes unnoticed because of lack of scrutiny. The Democrats favour a more comprehensive response that would protect the aged, regardless of where their care takes place.

Similarly the Government's narrow focus on physical and sexual abuse ignores the other types of abuse, such as psychological, financial and neglect, which older people are equally vulnerable to – whether in residential aged care, community care or even a hospital setting. The Government has a responsibility to respond effectively to all types of abuse and to implement strategies that will reduce the incidence of all forms of abuse. Additionally staff members that raise concerns about incidences of abuse should be afforded legal protection, regardless of the nature of that abuse.

Recommendation

That the Government develop a comprehensive approach to elder abuse which includes strategies to protect older people from all forms of abuse in residential and community settings.

That the legislation be amended to provide whistleblower protections to people who report, on reasonable grounds, any form of abuse or neglect.

The Australian Democrats also have reservations about the exclusive focus on mandatory reporting as the Government's response to what is a complex and multifaceted problem. In particular the Democrats argue that prevention rather than post-abuse legal responses is a preferable approach. Available overseas evidence indicates that mandatory reporting in itself will not guarantee improved safety. A more effective strategy would prioritise a strong education focus which informs older people of their rights and supports the carers of older people. Mandatory reporting should form part of a range of initiatives, rather than a solitary response. It is disappointing that the Government has failed to provide substantial investment in information and education on elder abuse, or to provide more resources for adequate community support services, including respite care.

Recommendation

That the Government fund a comprehensive education campaign for professionals, older people, their families and carers and the broader community.

That more resources are provided for community support and respite.

The Australian Democrats also share the concerns raised in many of the submissions to the Inquiry that this legislation undermines the autonomy and privacy of older individuals. In other circumstances the law assumes that competent adults can make their own decisions about whether or not to do anything about the abuse they experience. This legislation explicitly denies older individuals with decision making capacity this choice.

Interventions relating to abuse should be victim focused, with the interests of the victim taking precedence over those of the care provider or the Government. Individuals should be provided with all necessary information and relevant options and then encouraged and supported to make their own decisions, including the option to refuse to have the matter reported. Denying individuals this right based on their location of residence would seem to be a breach of their rights to determine who receives personal information about them. There is also the potential that such an approach will have negative consequences, including discouraging older people from seeking assistance if they believe their conversations will not be confidential.

Recommendation

That the legislation be amended to recognise the right of any competent older person to request confidentiality and privacy in relation to the reporting of abuse.

Given the lack of evidence concerning the effectiveness of mandatory reporting and the considerable resource implications for service providers, it would seem important to evaluate if this approach is an effective response to elder abuse.

Recommendation

That an independent review of the operation, effectiveness and implications of this legislation be made two years after the commencement of the Act.

Senator Lyn Allison
AD, Victoria

APPENDIX 1

Submissions received by the Committee

1 Australian & New Zealand Society for Geriatric Medicine (NSW)
2 Aged Care Lobby Group (SA)
3 COTA Over 50s (ACT)
4 The Aged-care Rights Service Inc (TARS) (NSW)
5 Liquor Hospitality and Miscellaneous Union (LHMU) (NSW)
6 Catholic Health Australia (ACT)
7 Australian Unity (VIC)
  - Additional information following hearing, received 8.3.07

8 Elder Rights Advocacy (VIC)
9 Aged & Community Services Australia (ACSA) (VIC)
  - Additional information following hearing, received 2.3.07

10 Aged Care Association Australia (ACAA) (ACT)
11 Aged Care Crisis Team
12 Health Services Union (HSU) VIC
13 Department of Health and Ageing (ACT)
  - Additional information dated 7.3.07

14 Australian Medical Association Limited (AMA) (ACT)
15 Herd, Mr Brian (QLD)

APPENDIX 2

Public Hearing

Thursday, 1 March 2007
Parliament House, Canberra

Committee Members in attendance

Senator Gary Humphries (Chair)	Senator the Hon Kay Patterson
Senator Claire Moore (Deputy Chair)	Senator Helen Polley
Senator Jan McLucas	

Witnesses

Elder Rights Advocacy

Ms Mary Lyttle, Chief Executive Officer

Mr Steve Aivaliotis, Senior Advocate

COTA over 50s

Ms Bettine Heathcote, Chair, National Policy Council

Ms Patricia Reeve, Executive Director, Policy

Ms Gayle Richards, National Policy Officer

Australian Unity

Mr Rohan Mead, Group Managing Director

Mr Derek McMillan, Group Executive, Retirement Living Services

Liquor Hospitality and Miscellaneous Union

Ms Laura Kelly, National Policy Officer *(via teleconference)*

Aged and Community Services Australia

Mr Greg Mundy, Chief Executive Officer

Aged Care Association Australia

Mr Rod Young, Chief Executive Officer

Australian Medical Association

Dr Peter Ford, Chair, AMA Committee on Care of Older People

Dr Mark Yates, President AMA Victoria

Department of Health and Ageing

Ms Carolyn Smith, First Assistant Secretary, Office of Aged Care Quality and Compliance

Mr Andrew Stuart, First Assistant Secretary, Ageing and Aged Care

Ms Carolyn Scheetz, Assistant Secretary, Compliance Branch, Office of Aged Care Quality and Compliance