



Report on  
Assistance and Support  
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# Executive Summary

This 'Achieve Support' discussion paper details a concept for the implementation of a fully integrated impairment related assistance and support assessment and allocation system and process as described by Simon Stevens, an independent disability consultant working in the adult social care and disability field. The intention is that the proposed idea would replace much of the policies, systems and structures of adult social care and disability related welfare benefits within the UK.

The concept can be seen as a combination of ideas and principles that has been brought together in a coordinated and coherent concept in how social care and disability related support, designed for children, young people, working aged adults and older people, can be delivered effectively and efficiently in a manner that is truly personalised and able to meet future funding requirements.

The first section of the paper outlines its aims and objectives and defines important terms in the context of the proposal including assistance and support, impairment and disability, outcomes, needs and solutions, basic rights, employment and personal journey. It explains why the paper has avoided using the term care because of the confusing way it is currently used.

The second section explores the history of disability including the creation of the welfare state and explores the independent living agenda including some of its history. The paper also explores the link between disability and welfare, as well as the current political environment. This background information is designed to set the scene of how we are arrived at this point and where the proposal fits in.

The third section lays the 14 foundation principles in which the proposal is built upon including inclusion, enablement, empowerment, choice, outcomes, co-production, responsibility, fairness, eligibility, portability, value for money, citizenship, and happiness. The paper feels it is important that the proposal has the right values for it to be successful and meaningful to be requirements of disabled and older people, as well as other stakeholders.

The fourth section explains the 'supporting outcomes' process including the remit of the process, setting the framework, the pathway of the process, the agencies that will be needed to be set up including Support England, the issue of Self-management, intermediary assistance and support, the assessment gateway including co-produced outcome focus assessments, the assistance and support plan and budget, implementation of the process, reviewing the process and exit strategies. This is the meat and potatoes of the report giving the fine details of how the process will work.

The fifth section discusses the implementation issues related to the proposal including the integration of existing funding streams, portability, the needs of differing age groups,

tackling limited resources, passporting and motability, what happens when things go wrong, maintaining standards, handling fraud and poor engagement, and getting people on board. It attempts to predict where potential barriers may exist and how they can be resolved.

The concluding section is a brief summary as well as an invitation for feedback on the paper.

The paper aims to be a starting point for discussion with the aim of providing an assistance and support assessment and allocation system and process to meet the needs of disabled and older people for which this country can be proud to have as a shining example of good practice.

### **Key Recommendations:**

- 1) The term 'care and support' is replaced by the term 'assistance and support' in all social care matters**
- 2) A legal framework for basic rights in terms of assistance and support is established**
- 3) Existing funding streams including Disability Living Allowance, Personal Independence Payments, part of Employment and Support Allowance, part of Carers Allowance, social services funding, Independent Living Fund, Access to Work, Continuing Healthcare, Disabled Students Allowance, SEN related funding and any other funding related to disability and impairment issues are all scrapped**
- 4) That all the funding mentioned are replaced by a single assistance and support assessment and allocation system and process.**
- 5) That a new national offer for people requiring assistance and support is established**
- 6) That many existing bodies managing the assistance and support of people with impairments and older people should be abolish.**
- 7) Several new bodies should be created including 'Office of Assistance and Support', 'Support England', local support bodies, 'Assist England' and local assistance abolished**
- 8) Effective intermediately assistance and support would be provided to meet the immediate requirements of individuals in order to reduce their longer-term requirements.**
- 9) There should be an effective single assessment gateway based on outcomes, not medical labels, co-produced with users and professionals.**
- 10) Everyone who needs assistance and/support should receive an assistance and support plan and therefore budget.**

**11) Assistance and Support Awards to be portable, relevant to people’s specific requirements**

# 1. Introduction

## 1.1 Overview

This 'Achieve Support' discussion paper details a concept for the implementation of a fully integrated impairment related assistance and support assessment and allocation system and process as described by Simon Stevens, an independent dysability consultant working in the adult social care and disability field.

The intention is that the proposed idea would replace much of the policies, systems and structures of adult social care and disability related welfare benefits within the UK. The concept can be seen as a combination of ideas and principles that has been brought together in a coordinated and coherent concept in how social care and impairment related support, designed for children, young people, working aged adults and older people, can be delivered effectively and efficiently in a manner that is truly personalised and able to meet future funding requirements.

The paper acknowledges that much of current social care policy regards adults, e.g. anyone over the aged of 18, as a single group. Since there is a greater number of older people, people over 65, than working aged adults, a generalisation of policy and practice assume that the needs of older people will naturally dominate the agenda, pushing working aged adults aside. The crux of the paper is a belief that the support needs of working aged adults should be seen differently to that of older adults in terms of its purpose and outcomes, but current policies often ignore these specific needs. This has implications in terms of assessment, eligibility, rights, responsibilities and other issues. It is important to clarifying what exactly support could look like to be more inclusive to everyone, and therefore the paper hopes to assist social care policy makers in meeting the needs of both working aged and older people.

This paper outlines 14 key foundation principals which make up the concept and the concept's proposed working process for implementation. The paper also offers ways in which the concept can be implemented to replace adult social care departments and other organisations. The ultimate goal is for the concept to be widely known and then adopted as mainstream social policy which is then used to form new Government policy, regulations and laws.

## 1.2 Aims and Objective

The central aim of the paper is to propose a new way to provide appropriate assistance and support to disabled and older people in a manner that is focused on helping them to meet their outcomes, including their responsibilities as citizens. The desire is to move away from a welfare system that is passive, requiring little action from disabled and older people, to one that is proactive to ensuring and maintaining their inclusion as fully contributing citizens.

The concept is intended to be an alternative to a wide range of existing welfare and social care schemes including disability benefits and social care payments. In terms of how disabled and older people are assessed, the proposal will provide an alternative to Simon Duffy's model of a resource allocation system based on self-assessment, and other current ideas. The concepts used will also be a continuation of what was achieved with Coventry's Individual Budgets pilot from 2007 in terms of outcome-focused assessments to develop a longer-term strategy.

The objectives of the proposal are to provide a new system of assessment and allocation that achieves inclusion for disabled and older people in a manner that is fair, effective, personalised, transparent and value for money. Attempting to achieve all these objectives in a single system would require it to be properly and accurately implemented and therefore this paper will offer an extensive focus on the finer details on how the proposal should be implemented.

It would be hoped that the process and system would benefit disabled and older people, as well as their families, because it will provide a single seamless experience in meeting of their impairment related requirements in a simple to understand and use. Along with a greater investment in removing environmental and attitudinal barriers, it is further hoped the process that will assist in eliminating disability related poverty and therefore improve the inclusion of disabled and older people as active citizens. The process and system will also benefit the government because it will provide a cost-effective way to meet the requirements of disabled and older people.

## 1.3 Définitions

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### 1.3.1 Introduction

Before going any further, it is important to properly define the central concepts to the proposal to ensure there is no confusion and that every reader can understand the intentions of the paper. Language is very important in the fields of disability, welfare and social care although it can be confusing as different people, organisations and situations can use the same term in different ways for different purposes, and it is therefore important that this paper duly defines how it intends to use relevant terms.

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### 1.3.2 Assistance and Support

The phrase 'assistance and support' is used as an updated replacement to the term 'care and support' as the description of the range of support and services disabled people or older people may receive in terms of social care, but to also include all impairment related payments and services someone may receive. The term care has been dropped because it is firstly a passive term that portrayed the idea of disabled and older people needing to be 'looked after', which is not compatible to the principles of this proposal. The term has also been too widely used by many people and organisations in many situations to refer to a wide range of meanings, that to keep the term would now be helpful and retain a level of confusion that is unhelpful.

In breaking down the phrase, 'assistance' can be defined as *the requirement and provision of direct personal assistance to a person physically or emotionally* and could be seen as including the activities carried out by unpaid family carers, care workers and personal assistants. Assistance can also include the provision of aids and equipment including wheelchairs, incontinence products and so on. In this manner, assistance can be seen as the first and closest level of help provided to disabled and other people, with the primary objective to keeping someone physically and emotionally healthy in the widest sense of the meaning including sleep, eating, keeping warm, maintaining hygiene and so on. Assistance is therefore about helping people not to move forward in their journey, but rather to prevent them from moving backward.

'Support' can therefore be defined as *the wider range of services and impairment related financial assistance disabled and older people may need to access to assist them with their inclusion as fully contributing citizens* including appropriate housing, transport, communication with others, education and employment opportunities and so on. While assistance may be obvious to see in terms of basic rights, support is less tangible but as important in terms of citizenship.

It is important to note that while this paper recognises the needs of people currently considered to be regarded as informal carers, this paper refers to them as families to recognise the interdependent relationship between impaired and non-impaired family relationships, that is not accurately reflected by the term carer. Also, this paper feels the term carer is unhelpful to the inclusion of people with impairments and older people.

### **Recommendations:**

**1) The term 'care and support' is replaced by the term 'assistance and support' in all social care matters**

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### 1.3.3 Impairment, Disability and Dysability

This paper defines impairment and disability in terms of the social model of disability as opposed to the medical model. In this context, impairment is defined as a biological difference, physically, intellectually or emotionally from the average person or norm that has no inherent negative connotations. Disability can be defined as the social consequences of having impairments including physical and attitudinal barriers. Disability is therefore regarded as a social construction which can be removed through changes in the built environment and societal behaviour indirectly, or through appropriate assistance and support to disabled people.

While the proposal recognises the importance of environmental factors, the focus is clearly on the best way to implement 'assistance and support', that helps to reduce the social consequences of disability.

It is important to understand that this paper works on the basis that not every impairment results in disability and therefore not every person who has one or more impairments can be considered to be a disabled person, since there needs to be social consequences from impairments to generate disability. It could therefore be seen that a majority of people experience impairment to some degree in one way or another, but that some impairments,

such as some sight difficulties, have been normalised by society, and this is why they cannot be considered to create disability. An example of this is people who need to use glasses may be considered impaired, but not disabled.

When the paper talks about 'disabled and older people', it is referring to a socio-political group that are going to be the most likely to require and benefit from assistance and support, acknowledging that specific disabled or older people may not require any assistance or support. The use of the term is merely for the purpose of identification as opposed to any desire to make generalisations. The term is however being used to include people who have long-term health issues who may not naturally define themselves as disabled or older.

It is important that notice of impairment, and those who are deemed to be need assistance and support, is as diverse as possible, and not stereotyped by the heroic client groups of former services. While people deems to be mildly impaired may not require formal assistance and support, they should still be able to access the system.

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### 1.3.4 Outcomes, Needs and Solutions

Current social care and welfare scheme talks about meeting people's needs, but often fail to define what is meant in a transparent manner. To understand needs properly, it is important to start with outcomes, as there are always specific outcomes even if they are not made clear. An outcome in this context of this paper means a potentially SMART (specific, measurable, attainable, realistic and timely) goal or objective related to someone's personal ambitions, situation and requirements, regardless of their impairment or health status. Whole some outcomes will be very clear to define, others will be more aspiration based. In establishing their outcomes, it is therefore possible to see what someone's needs may be by identifying their specific difficulties they have in fulfilling their outcomes in comparison to their non-disabled peers, so considering age, social background and other factors.

When the outcomes have not been disclosed or considered, like in many current social care assessments, then it is likely that the outcomes have been assumed by the assessor without the knowledge of the user, making it harder to establish their agreement or to deliver personalised assistance and support.

Once outcomes have been used to identify barriers to their achievement and generate a list of needs, then it is possible to match the needs with relevant solutions such as the provision of equipment or personal assistance, or interaction with specific services. When a list of solutions has been generated then it can be decided how they can be provided or funded, and by who. While some solutions may not be funded by the assessing agency, it is therefore possible using this method to establish who should be providing the solution, which may include users themselves.

It is important to understand what is an outcome, a need and a solution, and not to confuse them, which can easily happen. For example, a specific individual may believe they need a wheelchair, but this is in fact a solution that may come from a need to have personal mobility, from the outcome to being able to get out and about. In using the outcomes to barriers to needs to solutions framework, it is easier to understand and established people's specific requirements and how they could be met.

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### 1.3.5 Basic Rights

In the context of the paper, basic rights can be need as the minimum standards of living any person can expect. To make the notion of basic rights fair, transparent and universal, it is necessary to relate them to outcomes as opposed to needs or solution in order to be correctly and contextually accurate. An example would be it would more accurately to say someone should have a place to sleep, as opposed to having a bed, because someone may live with their parents or any other number of places where physically owning a bed is irrelevant. By making 'having a bed' a basic right it could require government agencies to purchase a bed for people regardless of their actual situation.

Other basic rights may include the right to a standard education, access to employment, access to public transport, the ability to be a consumer, all the rights under the Human Rights Act, access to health services, an ability to eat enough food, and so on. It is not the intention of the paper to properly define a list of basic rights but simply to acknowledge their existence.

A full breakdown of what the basic rights of a person may look like can be seen in Appendix A.

#### **Recommendations:**

**2) A legal framework for basic rights in terms of assistance and support is established**

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### 1.3.6 Employment

For the purposes of this paper, employment is defined in the widest possible terms as opposed as just referring to paid employment. In this context, employment relates to any kind of meaningful activity that helps others in one way or another, whether it is paid or unpaid, formally or informally recognised that provides benefit both to society and the individual 'worker'. If we regard education and training as well as indeed leisure activities as being 'helped' as a receiver of services as opposed to providing services, then we can see employment as the opposite of this. The notion of employment has been a central mechanism of Western society for over 1000 years and the desire to work, to help others in exchange for financial or other reward, is a part of human nature.

Therefore, the ability to work must be seen as a central goal for the majority of people whether that includes access to education and training opportunities, paid work, self-employment or volunteering. The notion of work should be seen in terms of a focus on the level of effort to first work towards obtaining employment, and then appreciate the activity of any employment, as opposed to the specific attainment of a level of financial remuneration, as it may be minimal for a variety of the reasons.

It is important to recognised that despite many people saying, 'they want to work but...', it is normal and okay to not see paid employment as your central goal in line in comparison with family and other priorities. However, while the welfare state can provide a level of

income, it is limited, and paid employment can only be the only real means of pulling yourself truly out of the realms of poverty.

The desire to support people with impairments into employment in all its forms has been made harder since 2010 because of the activities of the sick movement to demonise the activity. The left-wing media and a variety of manufactured research has used the 'benefit scrounger' rhetoric to make saying various people with impairments are having the potential to work as being something immoral.

This attitude that has now spread across the sick movement has created a form of institutionalised malingering, where people feel they have the right not to work because they have labelled themselves disabled, even if the state does not agree with them. This negative mindset has helped to make the benefit and social care systems, requiring the radical change proposed.

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### 1.3.7 Personal Journey

This paper proposes the concept of a personal journey as the emotional and intellectual development someone goes through during their life. In describing this as a personal journey, it enables individuals to understand their unique abilities and potential, and set goals accordingly, as well as understanding where they are in the totality of their life, and when they are heading.

The key to understanding personal journeys is that they are unique and personal to each individual, and cannot be compared and given relative value, since each journey has equal value regardless of how society perceives them. This means the film star and the taxi driver are equal in their contribution to society and that they are interdependent on each other, as we are all interdependent on everyone around us.

It is the intention of this paper to demonstrate that for the proposal to be successful, it has to support people to understand and manage their personal journey, as well as providing the support and tools to eliminate or reduce any impairment specific barriers in the way of them following their personal journey.

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### 1.3.8 Social Mobility

Social mobility can be seen as ability to move up and down the socially constructed notion of class and social standing. It is a belief that the situation you are born into does not need to define your whole existence. It is understood that a good education and an involvement of extra-curricular activities, as well as a positive attitude, can improve your social situation if you are willing to put the effort in.

For many people with impairments, especially people with lifelong impairments, social mobility can be more difficult due to the social impact of their impairment. Also, people with lifelong impairments are unlikely to have the opportunity to build up the same level of social capital as their non-impaired peers, or those who become impaired in later life. This means any work and solutions are often required to ensure an equality of service.

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### 1.3.9 Living

Living is defined in the context of the report relates as the components required in someone life for them to maintain a functional and 'good' life within the current construction of society.

In terms of how it relates to people who require assistance and support, a good starting point is the look at the '12 pillars' produced by the Independent Living model.

The "12 Pillars of Independent Living" are:

- appropriate and accessible information
- an adequate income
- appropriate and accessible health and social care provision
- a fully accessible transport system
- full access to the environment
- adequate provision of technical aids and equipment
- availability of accessible and adapted housing
- adequate provision of personal assistance
- availability of inclusive education and training
- equal opportunities for employment
- availability of independent advocacy and self-advocacy
- availability of peer counselling

While four decades since the pillars have been created, many people who need assistance and support do indeed have access to these components, but these have not been enough to achieve the full and meaningful inclusion they deserve. A core component of good inclusive living is self-autonomy. The 12 pillars are solution based and assumed people already have self-autonomy and does not call for assistance to provide it.

A fully comprehensive assistance and support system should to provide everyone with self-autonomy and should enable and empower them to achieve this if it is lacking.

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### 1.3.10 Independence

There are three ways independence can be defined in terms of people who need assistance and support. The first traditional medical model definition of independent is about doing physically able to do things for yourself like showering, dressing, cooking and so on. In the guise of rehabilitation, the focus of medical model designed assistance and support, assistance and support services would be focused on teaching people to do things for themselves as a central goal regardless of how much effort is needed and how long it takes.

The social model definition of independence, as used by the independent living, recognised that people who require assistance and support may indeed be physically or emotionally dependent on others to perform certain activities as we all are to some degree,

it does not mean they can not have control over how these are performed by using special equipment and employing personal assistants. Therefore, independence is defined solely in terms of exercising autonomy.

A third way to define independence is having time to yourself and reducing the time you need to be dependent on another person by using equipment and other solutions as there is a level of emotional involvement in person care that does not exist with other solutions. The independent living agenda has created a generation of people with impairments who have relied heavily on personal assistants and failed to see the new solutions around them like online shopping. As they fear change, their independence has become a dependency as it is hard for them to see the emotional benefits of time alone, still acknowledging they need personal assistants to some degree.

# 2 Background Information

## 2.1 History of Disability

In understanding that impairment is biological certainty and disability is a social construction, we can understand that impairment has existed since the dawn of mankind and its presence can be seen in the critical analysis of legends, fairytales and fictional material. Right up to the 17th Century within a feudal system of economics, contribution was measured in terms of the productional ability of families, as opposed to individuals, as land owners and others collected taxes from their tenants on an annual basis. As agriculture was the primary industry at the time, farms could be run by a family where all the members of the families had a role to play regardless of their age or ability.

This makes people with impairments, or those who survived the lack of any health services, had a role to play and therefore were not seen as disabled, it was simply not an issue. This is further supported by the fact there was no right or ability to be healthy and therefore impairment and disease was the norm.

The industrial revolution completely changed the situation because the required for individuals to work with machines which meant that they were suddenly being measured on their productively as individuals. Since factory owners were interested in maximising productivity and were now able to calculate the average amount of work they could expect an individual to be able to perform for the amount they were paid, it was now possible to identify people with impairments who were unable to perform to the average.

This was the creation of disability as a social construction, as specific people with impairments were identified as being unable to earn money within an industrial society and therefore requiring some kind of support from the state or charities. The notion of disability has remained with little revision as the mechanism and reason disabled people receive support today and can be seen in the way the UK's Work and Capability assessment is organised.

As the industrial revolution grew, so did the number of people with impairments grow as populations migrated from the countryside to the towns and cities. Within an era of increasing confidence in scientific endeavours and a lack of any notion of social justice in what was a class bias society, the answer to solving the growing social problem of disabled people was left to the expanding medical profession, who were charged with curing disabled people, and so the medical model of disability was born.

While the medical profession has made many advances that have improved the quality of life for people with many impairments, and assisted in the prevention of some impairments, many impairments have simply been untouched by scientific advances. It is only in recent years that the medical profession been comfortable to see impairment as a natural part of humanity. Before this time, there had been a great deal on experimentation done to many people with impairments, sometimes bordering on torture, in their obsession to find cures.

Since disabled people were deemed to be inherently inferior, a problem to resolved in mankind's quest for a scientific utopia, the argument followed that if they could not be cured, then they should be eradicated and this has led to the desire to identify abnormalities in foetuses to allow them to be aborted as a matter of course. While there has been little action to eradicate living disabled people in most societies, Adolf Hitler did kill 200,000 disabled people before the mass slaughter of Jews. There was however the desire to remove disabled people from mainstream society since they were regarded as inferior and useless to the development of society. This resulted in the establishment of special schools and residential institutions to manage them, many of which still remain in existence today.

The medical model remained as the dominant way disability was perceived until the 1970s when a group of disabled people became tired of the negative way they were being portrayed by many elements of society and started working together to form a new way of understanding disability. They argued that it was not impairment that made them naturally inferior but that their impairments meant gave them disadvantages because of their physical environment and the attitudes of others. They further argued that society, the environment and attitudes, is socially constructed and can therefore be changed accordingly, or reconstructed into what we now regard as the social model of disability. Support for the social model has grown since the 1970s and it is currently regarded as the dominant model politically. This has laid down the foundations for many current policies and legislation that has resulted in civil and human rights for disabled people, improvements in the built environment, and many other improvements to the opportunities that disabled people now enjoys.

With the advent of the social media and other factors, it could be argued that the current welfare reforms, which this paper will discuss in more detail, that there is a current informal movement of change occurring to further the inclusion of disabled people into mainstream society as fully contributing citizens and that proposal is just one of a number of initiatives interesting to discussing the next big social policy idea is in terms of disabled people.

## 2.2 Independent Living

The movement towards independent living started in America in the 1960s when students at University of Berkley who had spinal injuries were unhappy at living in residential care, which was the norm at that time. They fought to live independently by employing their own personal assistants. The idea slowly caught on, especially in the UK in the 1990s and this was seen with the implementation of direct payments in 1996 to enable disabled people requiring social care to have the money they needed to employ their own personal assistants and therefore for the most part, live in their own homes.

While it is generally accepted that independent living means not living in residential care, this can not be seen as the total meaning of the term. The independent living movement regards successful independent living as disabled people having appropriate access to information, peer support, housing, equipment, personal assistance, accessible transport and accessible environment.

While this has been successfully implemented and recognised in a wide range of social policies, these needs could be seen as not going far enough. One reason for this is a

solely rights-based approach can ignore the responsibilities that go along with fully citizenship. Therefore, if disabled people wish to be seen as equal and independent citizens, where the barriers to their participation have been removed, they must be take on the related responsibilities that includes education and employment, sometime not previously discussed in terms of independent living.

Therefore, it could be argued that the meaning of independent living for a 21st century audience is facing an identity crisis and that this paper and proposal is an attempt to describe what independent living could constitute in the future and how it could be implemented. The closure of the Independent Living Fund has been challenged using the principles of independent living by disabled activist although a detailed analysis could show that the fund may not meet the current and future expectations of what independent living could or should constitute.

Going further, it could be suggested that the concept of independent living as failed for the majority of people with impairments. While a minority of people with impairments, mainly with physical impairments and of working age, have benefited from the policies of independent living, this is because they already to the motivation to want to live independently and the social capital for this to be achieved.

For many people with impairments, the funding allocated in the name of independent living, like ILF, direct payments and personal health budgets, have actuality ended up under the management of families to care for their 'loved ones'. While this may not be an indication of any wrong doing, it does not exactly live up to the notion of independent living.

Even when someone is directly managing their own support, it does not necessarily mean they are living independently. Too much reliance of personal support, and the number of hours provided, as an indicator of the success of independent living can actuality lead to a form of self-oppress and dependency. This means that having too many hours of personal support may actually lead to people becoming dependent and disempowered, as opposed to achieving the goals of the principles of independent living.

The current problem is that the politics of austerity has lead the independent living movement to become defensive in protecting the principles of independent living. As a result, they have continually painting a rosy picture of the benefits of independent living and been unwillingness to acknowledged where it has failed, and what improvements can be made.

## 2.3 Disability and Welfare

Disability has been an important part of what is considered welfare since the creation of the welfare state in 1948 as disabled people have always benefited from assistance. However, for most part it has been provided on a medical model understanding of disability, particularly in terms of those who are unable to work in the traditional way. The welfare state works using the sick role, that is society accepts that people need a varying amount of time off from paid employment if they are sick, so long as they do everything possible to get better, which is why the NHS was created. Since someone pays national insurance, they are entitled to claim from the start when they are unwell.

Disabled people have until recently been treated in the same way, as unemployable, and therefore considered unable to contribute to society. The first signs of a shift towards a social model understanding of disability can be seen in 1992 with the creation of Disability Living Allowance (now Personal Independence Payments) and Disability Working Allowance (now part of Working Tax Credits and soon to be merged into Universal Credits) which gave provisional recognition that additional costs of disability although being paid as a benefit, give a compensational amount as opposed to any meaningful individual calculation as desired in this proposal.

Since 1997 there has been a recognition by the then Labour and now Conservative governments that more disabled people can access employment opportunities, with the right assistance and support, due to the changing nature of employment and the technological advances that have had occurred. The current government has been very insistent in the notion that disabled people who could work should not be left unnecessarily dependent on benefits for the rest of their lives, however the implementation of relevant policies has not been as successful as they would have liked, attracting extensive criticisms from all sides. In examining a proposal for a new assistance and support assessment and allocation system, the paper intends to pick up on the criticisms and ensure the same mistakes are not repeated.

## 2.4 The political environment

It could be argued be the relationship between disabled and older people and the state in terms of welfare benefits and social care is a hot potato that will high up on the agenda of all political parties. With the government's welfare reforms gradually being implemented under close scrutiny and the Care Bill/Act implemented in 2015, these are two issues affecting impaired and older people that may be still regarded as unfinished business. The rise of social media has made the discussion of issues easier but allowed a lot of individuals and organisations to lobby their own interests, making it harder and more complex.

Much of the opposition of to Welfare reforms has been fueled by an institutional medical model of disability where people remain insistent on disabled people being regarded as vulnerable people who can not work and therefore should not be made to work in the name of social justice. While there are good intentions to this, traditional welfare thinking, as conceptualised by the political left, can result in disabled people being regarded and treated as passive, therefore compromising their rights and responsibilities, including their access to relevant employment opportunity.

While Labour will want to improve what they see as the weak points of the welfare reforms, they are likely to wish to a similar direction of reducing unnecessary dependency, as well as tackling some of the root causes of poverty and other factors that causes exclusion for many impaired and older people.

It is important to understand how topic both PIP and ESA has become since 2010, especially in times of how they are assessed. The left-wing media has been harsh on the attacks on the system, using the misguided angry of newly impairment people and an anti-

inclusion movement to spread misinformation, causing distress and becoming a core factor in potential suicides.

While nothing is explicitly said, the left appears to be pushing for a more lenient system, where anyone who wants disability benefits can have them without challenge, built on very medical model values. This approach is likely going to be harmful for people with high support needs, who have no real voice currently, as well as harmful for the meaningful people with impairments.

This paper and proposal aims to be a political viable alternative to the state policies on welfare and social care, being a final big new idea to take the participation of disabled and older people to a whole new level by dramatically improving how assistance and support is assessed and allocated.

# 3. Foundation principals

## 3.1 Introduction

Before going into the details of the proposal for a single assistance and support assessment and allocation system, it is important for this paper to duly outline and explain the foundation principles in which the proposal is built upon. The foundation principles are used to ensure that every component of the system is implemented properly with a good understanding for the bigger picture, as well as the finer detail.

The foundation principals of this paper are a combination of traditional social work and social justice values, the core beliefs of the UK Independent Living movement, elements of the former 'New Labour' personalisation agenda and what could be described as the emerging values of a post social model thinking and theorisation. While these foundation principals can be duly evidenced and could lead to extensive research, this is not the purpose of this document, which is merely an initial discussion paper to be expanded upon.

## 3.2 Inclusion

Inclusion can be seen as the ability of a person who could be defined as 'being different' to practically be and psychologically feel included in their families, communities and society at large as a fully participating citizen who are able to take up their rights and responsibilities in a manner that is appropriate to their age, social background and culture.

The paper assumes it is the goal of any just society to desire all its citizens to be and feel included as much as possible. It is important that everyone fully understands what inclusion is and why it is important to society.

In the context of this paper, Inclusion can be facilitated through four main methods, the first two relating to the requirements of specific individuals while the last two relate to the society at large. It can be argued that full and meaningful inclusion can only be achieved if all four methods are implemented together to create the synergy required.

The first method is inclusion focused enablement, which is the provision of personalised equipment and support including wheelchairs and personal assistants. An individual should wherever possible have the ability to leave their home to take part in community activities such as shopping, sport activities, other leisure activities, and participation with voluntary organisations if needed, paid work or in other activities. Therefore, individuals need to be practically enabled to be included and so have a degree of responsibility to use that ability.

The second method is inclusion focused empowerment, which is the provision of psychological and behavioural development tools to allow individuals to feel able and

willing to exercise their rights and responsibilities as full citizens. It is important to understand that previous social policies such as special schools may have restricted a person's freedoms and expectations, and therefore they may not have previously understood their roles as citizens, therefore this would be a significant barrier to inclusion.

The third method is what is often called universal design or accessibility. This relates to the built environment and involves creating a more inclusive society that is able to practically meet the needs of people with differing needs who were previously not accommodated. While this often relates to the needs of wheelchair users, this can and could be extended in a whole range of needs and can include services like shopmobility and internet shopping. This can also be described as low level 'universal' social care as inclusion barriers are overcome without people necessarily realising.

The final method is the attitudinal acceptance of people with differing needs by communities and society. This is the most difficult to achieve and requires a behavioural change before a full attitudinal change can be achieved, which can be seen by the previous campaigns to wear seat belts and stop smoking. The portrayal of issues in the media can be key and can also be difficult to control. This acceptance needs to go beyond the awareness of specific issues, like hate crimes or the supposed rise in 'hatred' towards disabled people as a result of recent welfare reforms, which may deflect the issue, and explore the true inner acceptance of individuals by all aspects of society.

While national and local government agencies or other organisation may not have direct control of some of the factors required for inclusion, it is important they have a degree of focus on the external factors of an individual's inclusion into their community and work with other organisations on what could be seen as public or universal social care in a similar way to public health.

Finally, while inclusion can be seen in terms of a civil and human rights agenda, it must also be seen as a social responsibility that should be facilitated and enabled.

## 3.3 Enablement

Enablement is a process of providing individuals with practical skills, equipment, adaptations and where required personal assistance in order to enable them to carry out all the activities required for them to live and perform activities related to their personal outcomes.

After periods of trauma, significant ill health and during specific stages of progressive impairment, a period of re-enablement may be needed to assist them to reach their outcomes. This is a potentially intensive process to firstly to restore the level of function available to them to its most optimum and effective levels, secondly to assist individuals to adapt their lives to their new situation they face through the provision of specialist equipment and lastly to assist them in establishing what level of long term support may be required to ensure someone is fully enabled.

It is clear that support can not be provided to individuals for activities that they are able to do for themselves, such as providing wheelchairs to someone who is able to walk without any difficulties. It is however not always this straight forward and a sense of fairness and

understanding needs to be used. Firstly, people may need to be using the correct medication at the right levels in order to ensure that their functional potential can be maximised, which can be a harder task to do in practice. The level of medication or indeed any medical intervention required may need to be less as well as greater and suggests that it is important for social care organisations work with health organisations in providing coherent enablement strategies.

A second issue is to understand the difference between maximum functional ability and feasible activity. While someone may be able to perform a specific activity like run a mile or bake bread with concentration, supervision and encouragement provided in a controlled environment, the reality of performing the activity persistently and with meaningful purpose may differ. Issues like energy management and social context need to be taken into consideration to ensure that individuals are efficiently enabled to perform their desired outcomes in the long term. For example, a person who is capable of work may be prevented from working if exhausted from completing daily living tasks that they can do but with genuine difficulty. A small package of support may enable that individual to achieve their desired outcome of being a productive citizen.

It is important for individuals to understand what activities they are able to do consistently on a day to day basis, including the level of assistance and support they would require, in order to fulfil their desired outcomes, which they can call Plan A. It is important for them to understand what activities they can do without assistance or support in the short term to meet their immediate outcomes, just as when a personal assistant rings in sick, understanding additional assistance and support may be needed to restore their situation, and this can be referred to as Plan B. It is important to recognise in this context that just because an individual may be able to manage without assistance or support in the short term, it does not mean this can be sustained in the long-term, and so a Plan B, is just that, a understanding of what to do in an emergency.

Wherever required, enablement should be seen as an interdisciplinary process needing the involvement of a wide range of health and social care professionals working together to provide personalised support to the specific requirements of individuals. Before long term support can be assessed, determined and arranged, individuals have a duty and responsibility to participate in any enablement process offered to them to ensure they have reached their maximum potential and feasible function.

## 3.4 Empowerment

Empowerment relates to the self-motivational and psychological strength of individuals and how it enables people to enact their true personalised outcomes. It should be acknowledged individuals, particularly those with new or existing difficulties, may have psychological issues to overcome that may restrict their ability to be autonomous or have reduced ability to understand their situation to make fully consenting decisions about their personalised agenda.

It is important that individuals are firstly provided the skills to be as psychologically empowered as they are able to be through, when appropriate, personal development exercises, including grief management, goal setting, behavioural management and so on.

Depending on the individual, these exercises may be delivered informally or formally in one way or another.

It is secondly important that when individuals do not have the full capability to understand their situation without support, that appropriate support such as advocacy is provided to empower people to make decisions about their lives and their desired outcomes. With support from advocates, family members, staff and friends, individuals may not always need to have a full understanding of everything around them but merely have an opportunity to exercise choice and control on the issues that are important to them.

Empowerment is about gaining the ability to take responsibility as well as exercising rights and it is a shift of power that can be difficult to manage for staff, family and the individual themselves. Emotional Independence can only be gained when an individual is both enabled and empowered, but independence is a current strategy that only goes so far.

It is vital that empowerment is regarded as a policy and approach that a core to the values of being a citizen, and the notion of social mobility.

## 3.5 Choice (Risk Taking)

Choice is about the ability to have a finite or infinite number of options to decide upon that individuals should ideally understand in terms of their strengths, weaknesses, opportunities and threats. Artificial choice can be given when a person may only be offered 2 options, say apples or oranges, when there are other options which they are not told about or aware of, like bananas, grapes and so on.

Free choice is a difficult concept to realise as every choice will to some degree be limited to how informed an individual is, the actual availability of choice in a specific situation may indeed be limited or even perceived to be limited.

Real choice is only possible when people are able and willing to take responsibility for the decisions they are prepared to make. In this context, a person can decide to perform any action they are able to perform, including breaking the law, on the understanding they will need to take responsibility for their actions, e.g. they could be arrested and punished by the courts.

It should be the goal of relevant organisations, families and others to facilitate individual requiring support to have as much choice and control over their everyday living as they would if they did not support, as well as having a similar level of consequences from their choices. In this way, risk taking is owned by the individual as much as what would exist if no support was needed. It should be realised that for everyone, there is an illusion of choice such as the time we can go to bed, where in reality our situation and responsibilities can significantly restrict the choices we have.

The concept of risk is often used to restrict the choices of people requiring assistance and/or support. Artificial, unrealistic or unworkable risk evasion strategies, that are imposed upon people in social care services without their involvement, should be replaced by risk enablement strategies that both recognise an individual's right to take risks in a manner that is acceptable in an appropriate social, age and cultural context with the

responsibility to provide a degree of protection to individuals who may not have the ability to understand the full consequences of their actions in a manner that is helpful rather than divisive.

True risk enablement involves engaging with individuals and empowering them to have tools to manage the additional potential risks associated with having impairments and related assistance and support, such as the direct employment of personal assistants. Safeguarding must be regarded as a proactive as well as reactive process that works with individuals rather than sweeps them up into a system that can not inform them of the processes involved.

It is important that choice is seen to be and is allowed to be complex and informed. What people choose to wear at any specific time is based on many factors and it is only themselves who needs to understand how they choose to dress one way and not another. It is important that people who require assistance and support have the ability to make these kinds of complex informed choices.

Choice is a term that has political significance in current social care policy that needs to remain a key foundation of people's understanding in how the priorities of the welfare and social care agendas should be shaped. It should be also recognised that previous social policy has been implemented in a manner that has restricted, and sometimes highly restricted, personal choice, and therefore the provision of choice to individuals requiring assistance support should be as close as possible to the same level as individuals who do not need assistance and support appropriate to their age, situation and social background.

## 3.6 Outcomes Journey

Outcomes may be defined a new unit of measure for how successfully an individual's assistance and support package is and it is a major shift in the purpose and goals of welfare and social care for disabled and older people. Social care policy has over the last 60 years moved from a service led to a needs-led one to now an outcome focus model of assessment. Initially before the era of community care, many individuals requiring assistance or support were simply placed in residential care or day care services based on resources available and a very basic form of assessment. Community Care saw the innovation of individual care plans and the concept of meeting personal needs of individuals.

It can be realised that within a needs-led assessment, an individual's need is often defined from the perspective of the funder or provider of services and this may differ accordingly to the specific requirements of the definer. An example would be that an individual with moderate eating difficulties may not be seen as needing a bib when it came to providing them with the funding for one by a social services department but their care home or daycare provider may feel the individual needs a bib because it is helpful for their staff in terms of less work cleaning up.

In this context, it can be seen the need is a relative concept, as opposed to absolute, as the outcome is not often made clear and is set by the funder or provider without any involvement of the individuals involved. It is therefore the next step in the evolution of social care policy to look at outcomes as the goal for setting parameter in assessments.

When outcomes have been set, needs can be defined accordingly in order to allow the outcomes to be fulfilled. These 'outcome founded needs' can then be fulfilled by specific solutions as services or changes in individual's actions or behaviours, which may come under the responsibility of social service departments, other public or privately run services or the individual themselves.

In examining Maslow's hierarchy of needs, we can see outcomes being connected to the higher levels, where the desired outcomes often relate to self-fulfillment and mental wellbeing, which are built upon physical and more basic needs. In this way, the top outcomes should relate to larger long term goals that may not be immediately achievable but offer an evolutionary journey that mean physical and mental wellbeing needs are met.

In effectively determining an individual's outcomes, it is likely to be easier to have an open discussion of a person's most appropriate related needs and therefore services or support provided as both the individual and assessor can work towards back to the outcomes if there is any disagreement in the needs or support proposed. This process allows assessments to remain outcome focused. It is also that in reviewing the outcomes of any individual that there is always an assumption that they have the ability to reach any goal and perform any outcome that they are able to imagine regardless of how others may perceive their abilities. Anyone can only achieve goals and outcomes beyond their initial expectations if those who support them are open to the possibilities anyone can achieve.

It is important to see Outcome as a form of journey that may include what could be long term goals like paid employment or being elected to political office. The assessment and review processes should therefore be focused in seeing where people are on their journeys, if it is still the correct journey and if they are still in course in terms of meeting their outcomes.

## 3.7 Coproduction

Coproduction means the production of a project, product, service or, for this paper, a support plan by two or more parties working together with a sense of equality and fairness. The core benefit of coproduction is that it can provide a win win solution where each party feels they have achieved something they are happy with. True coproduction can not be seen to have been achieved if either party do not feel they have not had an equal or fair say in what decisions have been made. Coproduction means professionals must be prepared to share their power with the person they are working with.

The second major benefit of coproduction is that since both parties sign up to what is produced they share the responsibility to deliver its' outcomes. A traditional care assessment would be directly organised by the social worker or welfare assessor who would ask the individual specific questions and then inform them of what support they may have. This means the individual may perceive they were not fully involved in the decision made and may therefore create some protest for what they deem to be an unfair outcome and so not own the decision. A coproduced assessment will see both assessors and individuals working together and therefore this joint ownership of the decisions may avoid conflict after the assessment.

The final major benefit is unless there are specific changes to an individual's circumstances, the coproduction method of assessment is more likely to be solid and long lasting. Since the assessor and individual will feel happier that the result is as fair as possible, the need for a review initiated by either party is likely to be less. This means that while a coproduced assessment may be more time consuming initially, it is also likely to last longer and may result in easier and quicker reviews in the future.

In summary, coproduction is a method of assessment that has been proven by organisations like Coventry City Council and could assist in bringing individuals requiring assistance and support and assessing organisations together to take not only responsibility for the specific support provided to individuals but also the fair distribution of support resources for others. In allowing assessments to be more truthful and based on understanding, a new level of fairness can be created.

## 3.8 Responsibility

Responsibility has been mentioned in a number of other foundation principals and plays an important role in shifting the focus and purpose of assistance and support to individuals. The welfare state was first seen as discretionary assistance and a privilege of living in a civilised and wealthy country. As the welfare state becomes more established it has been and now is mostly seen as a right from being a UK citizen. It is now clear the welfare state was designed to support individuals who were perceived to be 'naturally' excluded from mainstream society and therefore merely needed to be 'looked after', reinforcing that exclusion in many cases.

The exclusion has now been challenged as society has been a better understanding the social construction of disability and a willingness for some excluded individuals to be included, which has led to the concepts of wellbeing being challenged. Current social policy now talks about people being included in activities like employment, however the change from a rights based system to a rights and responsibilities based system has not yet fully occurred.

Responsibility is important as it is a part of obtaining choice, equality and inclusion. People can not truly obtain rights without a willingness to take up the responsibilities that come with rights. Previously social policy, and the exclusion that resulted, may have restricted people's understanding of responsibility or rather their ability to exercise it. It is therefore crucial that responsibilities, a consequence of inclusion, are discussed and acknowledged during assessments and that individuals are supported in understanding and then taking up their responsibilities in association with their rights.

## 3.9 Fairness

Fairness is an overriding foundation principle that is about ensuring that the delivery of support to individuals is universally fair, that is the same mechanisms, values and decision making criteria are the same regardless of the individual involved. So, while the outcomes and support required may differ between individuals, a similar formula is used to ensure

people with similar outcomes and circumstances have a similar level of support even if it is used differently.

Achieving true fairness is difficult when it involves the discretionary assessment of one person by another person. However, fairness could be achieved by ensuring each decision can be seen in universal values. Primarily, a person's outcomes and support requirements, including the level of involvement from family members, should be measured in terms of what could be expected if the person did not have difficulties in terms of age, social background, family norms, sexual identity, educational potential and so on. In this way, any assistance and support provided can be seen in terms of bridging the gap between the individual with difficulties with the potential individual without difficulties.

The concept of fairness will also assist with the portability of support as people move from one place to another, also in terms of appeal systems, when the decisions of assessors need to be challenged and further explained. By linking fairness to social and cultural context as well as functional needs, it allows relevant organisations to justify the distribution of its resources.

## 3.10 Eligibility

Eligibility criteria are currently used by social services departments to decide who should and should not receive services from them. In using four levels of nationally agreed criteria, as specified by FACS (Fair Access to Care Services), social services make decisions of people's eligibility based on immediate need alone. The levels are low, moderate, substantial and critical. It is currently up to the discretion of each local authority to decide at what level they provide services, and at the discretion of each assessor to determine the level of need for the varying activities a person may require assistance with. This current system is only focused on immediate need, it has no preventive mechanism, and is seen to be willing to allow specific individuals' situations to deteriorate to a point when they then become eligible for services.

It is clear that any assistance and support assessment system would need some kind of eligibility criteria since no system could provide the level of assistance and support desired to any or every person requesting it without some fair process of limitation or rationing. Therefore, any system needs a clearly understandable and transparent means of determining eligibility. This paper proposes that any new eligibility criteria should be based on someone's outcomes, the degree of risk to requiring more assistance and support if some level of support is not provided immediately, and the length and degree of 'hardship' individuals and families would experience without care and support. This means that people's eligibility can not just be based on labels, or specific triggers but rather a collection of factors that make sense to everyone involved. The notion of 'reasonable hardship' relates to the fact if someone breaks their leg, without any complications, while they may benefit from some assistance and support, it is normal and therefore reasonable to them to experience a level of short term hardship and therefore should not be eligible for support. Deciding eligibility is often not that simple and any eligibility criteria decided upon will face its own difficulties.

In establishing a new eligibility criteria, it is important that it has been co-produced with all the stakeholders and that there is a wide consultation. It is important that suitable and

clear documentation is produced that is able to explain the eligibility criteria and its reasoning.

## 3.11 Portability

The paper proposes as detailed before that people feel more comfortable with assessments that are arranged locally, as opposed to being handled by a third party agency, which we can see with the failings of the Work Capacity Assessments. While assessments should be carried out locally, they should clearly follow agreed national standards and result in assistance and support packages that meet nationality set guidelines. One reason for this is so that the packages can be portable, this is taken with someone who decides for whatever reason to move from one part of the country to another.

There may be many reasons why someone may choose or may need to move, including obtaining employment opportunities, going to university or changes in their family situation, and therefore it is important that their right to freedom of movement is upheld. Currently, each local authority has a different way of administering and allocating assistance and support, and it is not current easy for anyone requiring assistance and support to determine if they will receive the same or similar level of support they are currently receiving until they have moved and then in the assessment process. This current level of uncertainty is unhelpful and potentially restricts the movement of people requiring assistance and support. Therefore, the portability of assistance and support packages is vital to any future assessment and allocation system.

In terms of implementing portability, it must be recognised that the process of moving home, especially from one part of the country to another, is likely to result in one of more changes of circumstances and this therefore while the principle of portability make sense, the reality is many individuals will need some and all of their support funding reviewed and potentially amended accordingly. However, it is important that any reassessment is performed on the same eligibility and standards as the current support funding individuals may receive.

## 3.12 Value for Money

It should be the requirement of any service funded by national or local government to ensure all of its activities deliver value for money, and this should be equally true for the provision of assistance and support. Value for money means that the amount of money spent on an activity has been worthwhile, in that it has achieved the desired outcomes for the best 'price' possible.

Value for Money is not about cutting costs regardless of the consequences, but a strategic system of reducing waste and ensuring the level of investment can produce the highest yield of results. It is sometimes about understanding when to invest a large amount of money initially can result in a longer stability of outcomes and outputs. An example would be a cheap washing machine may cost £50 but only last 12 months, while a washing

machine costing £150 may last 6 years, or £25 per year, working out to be double the value of money than the supposedly cheaper washing machine.

While the idea of considering the cost of providing assistance and support can be controversial, it is essential that cost is one of the factors to be considered. If cost is not considered, it can cause a greater focus on service led solutions, like residential care, as there is likely to restrict innovation and a requirement to research needs led and service led solutions which provide a better quality of outcome to users.

If a more cost effective solution is available that can meet the same outcomes or better, then it has to be considered as new technological solutions become available. An example of this may be a continued reliance on BSL translators as people when new technology may help reduce the need for them.

In terms of assistance and support assessments, it is about using cooperation and partnership working to receive agreement of solutions that are able to meet the desired outcomes of the person being assessed but in a manner that is value for money, and therefore may be deemed untraditional and/or creative. By focusing on outcomes and not being too territorial about specific solutions, both assessor and person being assessed should be able to develop a win win solution that is value for money, especially if the person being assessed feels confident about the decision making process and jointly responsible for ensuring value for money.

## 3.13 Citizenship

This paper talks a lot about citizenship and therefore it is one of the foundation principles. Citizenship is the status given to someone who is a member of a specific country or society, and it details the relationship between that person and the state in terms of their rights and responsibilities. Civil rights may include the right to education and employment opportunities, the right to live in a safe and clean environment, access to transport, access to welfare benefits and state pensions when needed, right to vote in local and general elections, and access to many aspects of society and civil life. Civil responsibilities may be the responsibility to complete a basic education, the responsibility to obey the laws of the land, the responsibility to behave in a manner appropriate to social norms, the responsibility to pay taxes and seek employment if taking advantage of unemployment benefits, and many other less obvious responsibilities.

For many reasons, impaired and older people have been excluded and so denied aspects of their citizenship both in terms of their rights and their responsibilities. It is the belief of this paper that any proposed assessment and allocation system should be aimed that people requiring assistance and support should have full access to their citizenship and their civil rights and responsibilities. Full inclusion is about full citizenship and therefore linked as foundation principles of this paper.

## 3.14 Happiness

In the context of this paper, Happiness is defined as a form of measurement that can be assessed by individuals themselves as to their level of satisfaction with the current state of their life, and the direction in which their life is heading. This understanding of happiness is not to be confused with the feeling of joy, as happiness can be seen more in terms of overall satisfaction or dissatisfaction with how aspects of their life is going. It could therefore be seen that happiness, in the way each individual perceives it to be, is the ultimate goal of any involvement and this should be reflected in any assistance and support assessment and allocation system.

Happiness should also be defined in the context of this report as both having unconditional self-worth and having the object of personal enlightenment, which are both important values of the assistance and support system.

# 4 Supporting outcomes process

## 4.1 Introduction

The Supporting Outcomes process is the title of the proposal to provide an assistance and support assessment and system that can be seen as a process that people requiring assistance and support are seen to travel through. The process includes maintaining public social care, the assessment of outcomes, needs, assistance and support, and the implementation of assistance and support that enables the full inclusion into society of disabled and older people. The purpose of the system and process which goes beyond the traditional roles of the welfare state and social service departments, including asking them to work with the local NHS (in whatever form) and other organisations to produce new clinical and support pathways, developing existing ones and establishing new ones, to better meet the physical and emotional journeys of impaired and other people.

The full implementation of the process would replace a lot of organisations and schemes that currently assist disabled and older people in the fields of welfare, social care, education and employment into a new organisation structure, built around the individual, that is focused on meeting the assistance and support needs of disabled and older people in terms of their outcomes and their full and meaningful inclusion as contributing citizens.

## 4.2 Remit of the Process

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### 4.2.1 Introduction

It is important to understand that the remit of the process and system is to focus to the additional assistance and support disabled and older people need, including all related impairment and disability costs, that may be required in comparison to their peers in terms of social background. While the aim of the process is to eliminate impairment and disability, poverty and disadvantage, the system is not interested in supporting general income, such as when people are currently unable to work, and leaves that issue to other policies to manage outside of remit of this paper.

This means that while it is proposed that Employment and Support Allowance (ESA) would be one of the welfare benefits to be merged into the system and process, it is only in terms of the impairment and disability related costs, and it is intended that the income component of the benefit would be handled by new income related policies. The system and process will replace a number of existing funding streams including Disability Living Allowance, Personal Independence Payments, part of Employment and Support

Allowance, part of Carers Allowance, social services funding, Independent Living Fund, Access to Work, Continuing Healthcare, Disabled Students Allowance, SEN related funding and any other funding related to disability and impairment issues.

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#### 4.2.2 Welfare and support split

It is important to clarify that any proposed assistance and support system is solely focused to the additional support someone with an impairment or health condition in a manner people without an impairment or health condition regardless of their background or income support. Therefore, even when the assistance and support is provided in the forms of a direct payment, it will not be intended as a form of income and the payment is intended to be spent solely on assistance and support.

The assistance and support system will clearly over the role of the current social care system, as this is how assistance and support is currently configured. It is also take over the parts of the current welfare system that related specific related to the extra costs of having an impairment, which includes Personal Independence Payments in full and some of the current configuration of Employment and Support Allowance.

The system will however not replace any income related payments provided because someone has an impairment or health condition that means they are currently not working, or for people who are not working because they are providing informal assistance and support. It could be imagined that in parallel with setting up this proposed assistance and support system, the welfare benefits system will be reformed as some form of basic inform.

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#### 4.2.3 Single process

The single process and system is intended to cover all ages, so supporting anyone with impairment related difficulties that result in a non-acute medical needs that can be handled or managed by NHS or other health services. This means the system does not intend to replace access to the majority of health service providing on a general basis, including prescriptions, although the purchasing of specific non-acute medical equipment, like wheelchairs and incontinence devices, would be brought into the process in allow increased choice and control.

The process would support individuals requiring support and assistance in the areas of education, employment, housing, transport, personal assistances and accessing community activities. It is proposed that is process would be available to anyone in whatever situation they are in, including if they are in hospital for long periods, and even prison.

Because of the issues of independence and state autonomy, the paper described the process and system in reference to how it could work in England primarily, although the process and system could be easily adapted to work in Wales, Scotland and Northern Ireland.

#### **Recommendations:**

3) Existing funding streams including Disability Living Allowance, Personal Independence Payments, part of Employment and Support Allowance, part of Carers Allowance, social services funding, Independent Living Fund, Access to Work, Continuing Healthcare, Disabled Students Allowance, SEN related funding and any other funding related to disability and impairment issues are all scrapped

4) That all the funding mentioned are replaced by a single assistance and support assessment and allocation system and process.

## 4.3 Setting the framework

The first phase of the Supporting Outcomes process is to set up the framework in which long term assistance and support can be discussed and agreement in the areas of strategy, advice, engagement, assessment of distribution. This should be done initially with social services departments along with relevant NHS bodies, national government and other organisations like Independent Living Fund and Access to Work until a new structure for assessing and allocating assistance and support is established.

As coined by the Labour Party in relation to their short lived National Care Services proposals in 2010, it should be about providing the general public with a 'new offer' in terms of assistance and support for disabled and older people. This offer as they proposed focused on a solution to the funding of social care for older adults, while this Supporting Outcomes process is focused on everyone regardless of age, including children. The reason for this is to ensure fairness and transparency, and to create a process and system that is a universal offer anyone can understand and use at any time in their life.

The framework should clearly and openly set out the rights and responsibility of all individuals in which the assessment and allocation system will assist them to achieve and maintain. The primary criteria to consider in relation to outcomes should be to fulfil an appropriate, reasonable and meaningful contribution to their community and society in any way they can. This would be assessed from the idea that paid employment and/or an active family role is an ideal contribution and evaluated downwards from this point in a manner which values the fulfilment of any potential contribution however small.

In using an outcome focus, the framework should not use a specific resource allocation system that is simply based on perceived function formulated to meet assumed need as this has the potential to ignore a whole range of factors which may increase or decrease the actual support required. The apparent simplification of resource allocation can result in a poor assessment process leading to potentially many problems with individuals in the future. On this basis, the specific allocation of resources and support should be at the discretion of relevant assessors and should also avoid label based or points focused assessments. The decision-making process used in assessments should be made clear, transparent and public, so that everyone understands the 'offer' which is being made. The process will also need to have some form of eligibility criteria based on situational triggers and functional potential.

The framework should form a clear pathway with any individual can use without prejudice to obtain the level of assistance and support they require within the assessment and allocation system provided. Individuals should fully understand that by claiming their rights to assistance and support they have responsibilities to fulfil any expectations are made

upon them. The framework should not appear hostile, unhelpful or 'mean' but rather fair, honest and open acknowledging the opportunities available as well as the realities of any resource limited funding process.

It should be explained clarify to all stakeholders that the outcomes are seen as a set of short term and long term goals, some of which like obtaining paid employment, may be lifelong goals. The aim of the system is all meet all the extra costs of meeting these goals because of an impairment or illness, in line with expectations of their peers in terms of work and lifestyle.

An important part of the framework should be that along side the assistance and support assessment and allocation system and process should be a systematic investment into removing environmental and attitudinal barriers in the greater detail than currently. This should include independently researching the less obvious barriers to inclusion and citizen participation, with the view of reducing the personal costs someone experiences as a result of having an impairment as far as possible, by ensuring suitable funding is provided to make mainstream and universal services as accessible as possible. It should be recognised that despite as much investment as possible, there will still be a level of personal cost that still needs to be picked up within the assistance and support funding.

It is important that the general public is given as much knowledge of the framework and that there is a wide range of on-going consultation with the general public, as well as those using the process and system.

#### **Recommendations:**

**5) That a new national offer for people requiring assistance and support is established**

## 4.3 The Pathway

The pathway can be seen as the stages of the journey someone using the assistance and support assessment and allocation system may experience from their own specific situation, that would also include aspects of Health and other services, to create a seamless experience and so better supporting an individual's physical and emotional journey.

Each individual will have their own specific pathway that requires differing types and amounts of assistance and support to be provided at each stage to ensure they receive what they need when they need it. The potential pathway for someone who has had a serious injury could look like this, including some or all of the stages shown;

Injury > Acute care > Rehabilitation > Intermediate Care > Recovery > Stability > Enablement > Empowerment > Education > Employment > Contribution > Family Life > Self worth > Happiness

This example shows how someone who has experienced a serious injury, such as from a road traffic accident, can travel through the assistance and support process in a number of

stages. The stages may be managed by one or more organisations, such as hospitals, rehabilitation centres, and specific assessment and support teams. Some stages may require a range of directly provided services, while other stages may be managed using the single payment, giving individuals choice and control. It should be in remit of the organisations providing assistance and support to individuals at each stage to help them to move effectively onto the next stage of their journey.

Another potential pathway journey may include the whole life journeys for someone with a long term impairment that would include all stages of their life including going to school, college, university, getting a job, getting married, having a family, retiring and so on. It is important that the pathway concept is not used to push individuals into a rigid notion of conformity as an individual's own pathway may be unique, unpredictable and ever changing, but it is important to understand the notion of progression.

There will be one or more pathways designed for children with impairments, such as a pathway through the education system from 3 years to 18 years. The assistant and support funding would be what children with impairments need at school, at home and elsewhere to fulfil their outcomes, that may include having a meaningful education, to have a fulfilled social life, and being a valued member of their family. The pathway would only deal with assistance and support issues and would leave matters relating specifically to safeguarding and 'children in need' issues to other agencies to manage.

## 4.4 The agencies

### 4.4.1 Introduction

The full implementation of the Supporting Outcomes process and system would require a new set of agencies and other organisations to be created would replace some of the roles of local social services and education authorities, some of the benefits managed with DWP all of Independent Living Fund, all of Access to Work, Access to Elected Fund and some NHS funding streams. By merging all impairment and disability related funding streams in a single coherent system, there should firstly be benefits in costs and effectiveness alone just by merging these streams together as it will result in a single assessment and allocation system. This will enable a more accessible and understandable process and system that is not restricted by the baggage of existing organisations.

The creation of new set of organisations enables them to be built upon a new set of values that includes co-production and the involvement of disabled and older people in their design and implementation, potentially making them more trustworthy. Their creation should be steady enough to enable policies and practices to be fully developed, and there should be an effective and transparent plan and mechanism to transfer assistance and support from the current arrangements to the new arrangements and ensures user involvement and aimed to ensure the trust and confidence of everyone involved. The language of the transfer should be one of making improvement and all parties should be provided the assurances they may require to get on board with the reorganisation.

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#### 4.4.2 Office for Assistance and Support

The Office for Assistance and Support would be an overriding body for all assistance and support issues, as a part of the Department of Health, and would manage over-arching policy development under the direction of Government Ministers and with the involvement of all relevant stakeholders. The body would have overall responsibility for the Assistance and Support Assessment and Allocation System, as well as the regulation of assistance and support services and the commissioning of directly provided services. This would include allocating over-riding budgets, creating and managing policies, collecting statistics and other research, and examining the development of specific issues as their discretion.

The body will encompass and remain responsible for everything to do with assistance and support issues for disabled and older people, although it does not have any direct remit to operate the assessment and allocation system, or run any services directly. It would however be the managing body for Support England, Assist England, and other agencies detailed below. It will however have an engagement programme that will include the involvement of disabled and older people.

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#### 4.4.3 Support England

Support England will be the agency responsible for the management and regulation of the assistance and support assessment and allocation system, including its structure and procedures, setting national standards, regulation of assessors and informing the public about the system. Support England will be the governing body for a network of local Support organisations who will manage the assessment of individuals. The body will not provide assessments to individuals directly but coordinate the national framework in which assessments will be carried out. The body will be a new organisation that will replace existing functions in other government bodies related to assistance and support allocation and assessment within DHSE, DWP and DfE.

The purpose of the body is to ensure consistency, fairness and transparency across the whole of England and within the network of Support organisation in terms of both assessments and how funding is allocated. It will oversee a national complaints and appeal system and will monitor the performance of local Support agencies. The body will have a number of impairment specific and issue specific working groups made up from users and professionals to continuously monitor and improve guidelines for example on diabetes, cerebral palsy, support in prisons. These working groups will look into all aspects of the system, ensuring the system remains responsive to the needs of its stakeholders in a manner that retains fairness and value for money.

The trustees of the body should be made up from a wide range of stakeholders including representatives of the Office for Assistance and Support, the network of local Support Agencies, national stakeholder groups, and an elected user representative.

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#### 4.4.4 Support Local

The everyday implementation of the Assistance and Support Assessment and Allocation System will be left to the network of local Support agencies, such as “Support Coventry” or “Support West Sussex”, most likely developing out of existing adult social services, and following the boundaries of current local authorities. These would be independent organisations that would replace local adult social services departments but would not be connected with local government bodies, although will work with them as one of many stakeholders.

Each local Support agency would commission specialist teams to providing assessments, makes awards to individuals and administer the allocation of funding in a manner that is fair and transparent according to National guidelines. To keep the system fair, the processes of assessment and allocations will be kept separate.

The assessment and provision of enablement and empowerment services will be carried out by local specialist teams that are commissioned to meet the needs of specific individuals, that could be according to their age, social situation or impairment, So this means there may be a young children’s team, a 19+ transition team, a working adults team, a hospital discharge team and an older person’s team. The aim is that each team has suitable experience and experience to support specific individuals with specific stages of their journey and therefore individuals may be transferred from one team or other where their situation changes.

The teams may be commissioned from existing third sector or commercial organisations, or newly formed organisations, and would remain independent from the support agencies. However, the teams would be required to provide a local service that was responsive and providing people receiving assessments, a single point of control for the stages of the process they are managing. To achieve this, it is important that the specialist teams are commissioned from organisations that are co-led by service users and professionals to ensure that can effectively provide an effective service. A home visit for the first assessment should always ideally happen wherever possible, or at the location that is comfortable for the person being assessed. The team will provide a report from people’s assessments, with their agreements, and these will be submitted as an electronic report to the local Support body for a decision of their local funding panel(s). The funding panel(s) will be made up of professionals, as well as trained and paid service users, who will benchmark the applications for support in line with national eligibility criteria, and an offer will be made accordingly.

When an offer has been accepted, the funding will be administered by the Support body, who will request the specialist team to carry out reviews and other monitoring activities. The level of funding being requested will determine if the offer can be approved by just one member of a funding panel, for low value requests, or a full meeting for high value requests. Some applications may result in a counter-offer may be proposed from the funding body, offering a reduced amount of funding or make suggestions of the specifications of the application. If a funding application is fully rejected, the panel will be required to provide feedback to the specialist team and applicants, so they can amend their application accordingly. The number of funding panels for each Support body will be dependent of the demographics and requirements of the area they are responsible for.

Each Support Body will be primarily accountable to Support England and therefore set up and answering to the Secretary of State, and subject to annual reviews. They will be required to be able to justify their decisions made in line with national criteria in a manner

that is both fair and flexible. There will also be an independent complaints and appeals system.

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#### 4.4.5 Assist England

Assist England will be responsible the regulation of assistance and support services, the development of the assistance and support market and commissioning of national directly provided assistance and support services such as specialist enablement services. Assist England would replace Care Quality Commission, Social Care Institute for Excellence, Skills for Care and other organisations as the single body for the regulation of assistance and support services, including Care homes, Care Agencies and many other services. Since it will be assumed that for the most part, services will be paid via direct funding to individuals, it will see a definite split between commissioning and regulations, other than in the area of health services and acute to intermediate social care services.

Assist England will manage the setting of national standards for assistance and support services and staff, the registration of services and staff, monitoring and inspection standards and guidance. It will also coordinate a network of local Assist bodies that would carry out the various activities. The full details of how Assist England would operate is outside the remit of this paper.

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#### 4.4.6 Assist Local

The everyday monitoring and inspection of assistance and support services, as well as local market development, will be carried out by a network of local Assist bodies, like “Assist Coventry” and “Assist West Sussex”. The full details of how local Assist bodies would operate is outside the remit of this paper.

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#### 4.4.7 Personal Assistance Fund

It is important for continuity nationally and transparent, it is important that the assistance and support assessment process, how someone is assessed as needing assistance and support at a local level, is separate from the actual funding provided to individuals to spend on their assistance and support.

The personal assistance fund will nationally administered fund to meet the formal assistance and support costs of everyone in the system. This means that while the assistance and support someone receives will be assessed and administered locally, it will be using national funded. The applications to the fund will be internally done by the local bodies which individuals will receive the fund will not need to fully understand.

The purpose of the fund to ensuring fairness nationally where the same criteria is used and so avoiding a postcode lottery.

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#### 4.4.8 Other Agencies

It is clearly like that the new structure for Assistance and Support would require a range of other agencies to be created or mandated with new responsibilities along side the core structure listed above to handle issues like complaints, appeals, research and so on. It is not possible to determine these bodies until the implementation of the new structure has progressed further and therefore it is outside the remit of this paper.

#### **Recommendations:**

**6) That many existing bodies managing the assistance and support of disabled and older people should be bodies**

**7) A number of new bodies should be created including 'Office of Assistance and Support', 'Support England', local support bodies, 'Assist England' and local assistance bodies**

## 4.5 Mainstream support

Before the whole issue of assistance and support can be formalised, it is important that they are policies and practises in place in the whole of society to support various low level needs of the people with impairments or illnesses in a manner that makes them as mainstream as possible, so facilitates that are provide universally as a matter of course.

This has already happened in terms of how the built environment has become more accessible for people with various impairments like wheelchairs users. The expectations of what should be universal is steadily increasing and an example of this is current campaigning for 'changing places' toilets.

It is also starting to happen with a growth in online and other mainstream services that have an incidental knock on benefit for people who may require assistance and support. This includes online shopping, online food delivery, online laundry services, technology like siri and alexa. This technology and services are likely to naturally grow and develop in a manner that will resolve many low level assistance and support without realising it, and in a way that can not be managed or planned.

## 4.6 Self-Management

Once the framework for the assistance and support assessment and allocation process and system has been established and the structure required has been put in place, then it is important to focus on the main components of the system. The primary one of these after mainstream support is Self Management.

Self Management relates to how individuals and families can manage their own assistance and support before any requirement for a formal intervention to be carried and could be seen in terms of 'public social care', in a similar way to public health.

The NHS was created in 1948 in an era when individuals were mostly defined as either well or unwell. If the individual was unwell, it was the responsibility of the NHS to find out what was wrong with them and fixed it, where it was assumed the individual had little knowledge or involvement in their health. If someone could not be cured they remained ill until they died. Now there is a greater understanding of the body and health issues so that there is now an increasing awareness of the need for individuals to be more aware of their own health and how they can assist in managing their health to prevent it from 'breaking down' or rather slow down the process. This shift of focus is slowly developing and creates a new rights and responsibility basis for health services.

The focus needs to also occur with assistance and support, where individuals need to understand that with right comes the responsibility to 'self-manage' their requirements as far as possible. This should not mean assistance and support funders should reduce funds provided to individuals, or increase the reliance of informal care to reduce costs, but rather it is about creating an environment where assistance and support issues are widely discussed and there is information widely available as well as cultural awareness on issues like equipment, services and other self management tools.

It is the current perception, reinforced in the media, that when a person becomes long term ill or impaired, their specific members of their family will be expected to give up their current role in order to become the full time unpaid informal 'lone' carer without support from others. In this context, the individual requiring support may be deemed to be passive and voiceless in their new role of a dependent person, while the public concern is focused on the informal carer who is deemed active in taking on the burden of looking after the newly dependent person. In this viewpoint of dependency, it is difficult to inject a rights and responsibility focus on the person with difficulties in a manner that could be perceived as fair. The focus should therefore shift into recognising and supporting the independency of the family unit.

It must be realised that while in some cases assistance and support would be provided to an individual who has no family, or no meaningful contact with their families who are active in their lives, in many other cases, an individual will have active family that is involved in their lives and they would have a family role they fulfil as wives, husbands, sons, daughters and so on. Currently, an individual is assessed as a single unit while the support may be managed by their 'carer', who indirectly benefits from the assistance and support provided. This can create a conflict of interest between the needs and outcomes of the individual and their family, and well as providing potential confusion for those who are providing support.

The carer/cared rhetoric is a recent social construction that is harmful to the coherence of families where each member has an interdependent role. It is therefore important that in term of this assistance and support strategy and any concept of self management, that the family unit in terms of interdependency is considered in whatever combination that may exist in without the notion of carer or cared for.

It is therefore important to see that a core aim of assistance and support is to ensure families can maintain their functional roles and each individual in the family is enabled and empowered to fulfil their family roles and their individual roles in a way that is personalised to their personal and collective outcomes. It may be the role of the assessors to establish a balance between the requirements of each family member in terms of the support provided.

Whether a person lives alone or with a family unit, it is clear that there are activities of self assistance and support within family should be socially and culturally acceptable, such as the belief that a single adult within a family unit may prepare the meals regardless if other adults are functionally as able to physically prepare them themselves. Therefore, no social care intervention could be deemed necessarily when the family unit is perceived to be functioning or functionable. It however must be deemed socially inappropriate for adult aged children with difficulties denied their rights opportunities and responsibilities by being to be functionally supported as young people and a transition of the family unit may be required to allow their independence to form and flourish.

It is often deemed that the most appropriate solution to offer a family is 'respite care', where a break from a 'difficult' situation is offered as opposed to actually trying to resolve the difficulty. An example of this may put be when supporting family members are being denied sleep because of the sleeping difficulties on their child. While respite care may offer a brief unnatural break from the situation, it would be better to try to resolve the sleeping issue for a long term resolution.

It must also be accepted that there are socially and culturally acceptable disruptions to the roles and responsibilities within a family unit which also does not warrant an assistance and support intervention, which may be if one adult member becomes unwell for a short time, then other family members will take on additional roles during that time. Within this context, it is firstly important to understand at what point a disruption can be deemed to be unable to be self managed on a long term basis. It is secondly important to provide a framework in which self management is not only encouraged but also supported through services to comfortably grow. It is important that children and young people do not take on or are asked to provide informal caring roles that goes beyond what is culturally acceptable in families who have no individuals with difficulties.

Self management of assistance and support does not mean leaving individuals or families to cope on their own without any kind of support. It however means creating a public awareness of assistance and support, and what tools, techniques and services are available to support individuals and families in managing their requirements before a formal intervention is requested or required. In this manner the public acceptance of what is perceived to be the responsibility of individual and families to manage themselves in terms of assistance and support can increase in the way it has does with health.

The first formal interaction between local Support bodies and individuals should be in terms of information and direction. Before a formal intervention can be approached or considered, individuals and their representatives need information, advice, directions and guidance on a number of matters relating to issues of assistance and support. It is important this information is given as a right.

The first matter is to have an understanding of what assistance and support is, what its aims, objectives and purposes are, and how it is relevant to the lives of individuals. In the same way that individuals have a general understanding of the police or hospitals and how to use them even if they do not have any personal experience of them. Currently, the role of social services department is not widely known amongst the general public, who may have unrealistic expectations based on myths. In order to ensure assistance and support is more effective, there needs to be more awareness by the public so they more are selective in their contact with local Support bodies. Other professional bodies like the

police also need greater training of what assistance and support professionals do and do not do.

The second matter is to provide people with extensive information that would assist individuals and families to manage their assistance and support requirements. This would include providing information on what aids and equipment are available for self purchase and how they can be used, tools for informal self enablement and empowerment, and how to recognise when there are problems that may require an informal or formal assistance and support intervention.

The final matter is detailed information on what the assistance and support 'offer' is being made nationally and locally to individuals in terms of what exactly being offered, who will be eligible and under what circumstances, how individuals and families will be assessed and how other potential support will be provided. By being very clear about the 'offer' and how it can be used, it is likely to empower the right individuals to seek assistance and avoid individuals who are clearly not eligible from requesting assistance.

In supporting Support England and local Support bodies to have a higher public profile, this can generate a new public understanding of assistance and support that can avoid the current mystery and frustration that some individuals may experience. The provision of extensive information will enable and empower individuals to make better decisions about their assistance and support requirements. This should include the involvement of GPs and health care provisions, to ensure they understand the assistance and support system and how they are play their role in the process.

## 4.6 Intermediary Assistance and Support

Intermediary assistance and support can be seen as the requirements someone may have just after leaving an acute care situation, like being in hospital, and before longer term assistance and support needs can be established. It is a period of daily change and development where a payment in lieu of services, as proposed for people with longer term requirements, is unworkable and a range of directly provided and instantly available services is required to assist in someone's rehabilitation and enablement journeys. Intermediary Assistance and Support packages should be arranged as a part of any complex discharge from an acute setting to ensure a continuous progress through someone's unique journey.

Therefore it is proposed that individuals who require short term intermediary assistance and support will not be eligible to apply for a single assistance and support payment, unless they have existing long term requirements, but will instead have flexible directly provided services provided that is able to meet their continuously changing needs and outcomes, as they progress to a more stable state of being and reach a point when longer term assistance and support requirements can be identified. They will also have access to low value interim payments to cover their immediate impairment and disability costs, outside what can be directly provided to them. Both the services and interim payments will be assessed by specific members of the rehabilitation and enablement teams supporting them on behalf of the local support bodies. The assessments will be informal and sensitive to the situations people are in, with the view in ensuring a speedy and effective recovery to full health or a state of recovery,

The aim of intermediary assistance and support, funded a mixture of health as well as assistance and support budgets is to provide people within the early stages of their impairment journey precisely what they require in terms of assistance and support when they require it to speed up their physical and emotional journey wherever possible, as well as reducing the level of long term assistance and support that may be required. It is hoped that by eliminating the battle to receive appropriate assistance and support at these early stages, it will assist individuals to psychologically heal faster in terms of their changing identity and therefore be in a better state to relinquish any level of assistance and support that may no longer be required. This process must also be assisted by the appropriate use of enablement and empowerment tools.

Enablement and Empowerment tools also need to be used as a part of the 'discharge' from Intermediary assistance and support packages and the start of any long term assistance and support payments that may be required. It is important that an individual's emotional readiness to be discharged as well as physical readiness is also considered to ensure their cooperation towards a position transfer, as opposed to causing unnecessary fear and stress.

Intermediary assistance and support services and funding will be seen as the coalface of where the assistance and support assessment and allocation system meets health services in a matter that is integrated and appears seamless to people who are transferring from acute health services to intermediary services and then into longer term funding. This is where an integration approach with joint working will be useful and required as a gateway into longer term funding.

#### **Recommendations:**

**8) Effective intermediately assistance and support would be provided to met the immediate requirements of individuals in order to reduce their longer term requirements.**

## 4.7 Assessment Pathway

### 4.7.1 Introduction

The Assessment Gateway can be seen as the core component of the assistance and support assessment and allocation process and system. This gateway is the assessment of disabled and older people's longer term assistance and support needs, including impairment and disability related costs, and the impact upon their immediate families.

The process will not be accessible to individuals receiving acute or intermediate assistance and support unless they have a pre-existing long term assistance and support requirement. The assessment process as a whole can look like this;

Outcomes > Challenges > Requirements > Solutions > Proposal > Offer > Award

It clearly has to be understood that the journey through this assessment process may often be more complex than this, with steps forwards and backwards, going in many directions with sometimes conflicting agendas between individuals and the families. It is the role of the assessments and others to successfully navigate through this.

Before any full assessment can be carried out, individuals need to go through some level of filter system or pre-assessment in order to ensure that an assistance and support intervention will be suitable and appropriate. A filter system would replace the current system of eligibility, which can be seen as unclear and unspecific. The filter system should be clear, specific and universally fair. There are four factors that must be considered, or gateways to clear, before a full assessment should be carried out.

The first is clearly that an individual who is requiring the assessment should have an impairment or long term condition which has an enduring impact on ability to achieve their outcomes as discussed above. While for a majority of cases, the impairments a person has would be very clear. However, in some cases, the impairment will not be so obvious and therefore a clear national definition of minimum eligible level of impairment which specifically related to the need for an assistance and support intervention must be established that result in non-medical difficulties. In examining existing laws, this definition needs to relate to a long standing and/or significant functional physical, learning, sensory or behavioural difficulty that results in actual or potential restrictions to life opportunities or experience within the social, cultural and economic contextual background provided.

The second factor is building on the fact an individual has an impairment at the time of an assessment, there is an actual loss or potential risk of loss of activity related to the fulfilment of their desired outcomes in a manner which triggers a concern by the gateway assessor. It will include the potential loss or actual loss of employment or educational opportunity if personal support is not provided or a difficulty in fulfilling their family roles. It will also include difficulties in maintaining basic outcomes like personal hygiene, eating and sleeping. This importance of the actual or potential loss will be determined by the individual themselves.

The third factor is that in breaking down the outcomes defined by the individual, that there are clear needs that could be met by an assistance and support intervention such as providing personal assistance. The big picture must be able to equate to basic needs like maintaining personal hygiene and nourishment that builds up into performing meaningful activities which in turn fulfil the individual's desired outcome.

The fourth and final factor is to ensure that there is not an immediate or obvious alternative to what can be provided by local Support bodies can provide that individuals and families have a responsibility to seek out and investigate before returning to the assessor to request support. This does not necessarily include any formal enablement or empowerment services as this would be assessed as a part of any assistance and support intervention.

The gateway system can be done directly between a duty assessor and the individual or their representative by phone or email quickly and in most cases without the need for a home visit unless triggered from another activity. It may be triggered from a referral from a GP and other health professionals, which will add weight to its priority as a case. This will acknowledge their role in the process as an integrated process with social outcomes.

If the individual or representative feels that the need for an assessment was unfairly rejected, then a face to face meeting may be required to fully establish the details of the concerns and to determine what alternative services may be available if the local Support body can not help.

It is important to understand this new assistance and support assessment and allocation, the level of impairment needed to receive assistance and support is likely to be considerably less than under the current criteria set by local authorities because it will include people currently eligible for Disabled Living Allowance or Personal Independence Payment who may not be eligible for social care.

### **Recommendations:**

**9) There should be an effective single assessment gateway based on outcomes, not medical labels, co-produced with users and professionals.**

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#### 4.7.2 Initial Self Assessment

Once the assessment team has agreed with an individual or family to perform a full assessment, the next stage is for a self assessment or assessments to be produced. There may be times where the urgency of the situation and need for assistance and support means an emergency assessment is required, and there is no time to do a self-assessment.

Within a family situation, each member of the family may wish to produce their own self assessments so that a total picture of the situation can be produced. The assessment can be produced by themselves unaided or with support from representatives and others, and may be in a standard format provided by the assessor or in a whole range of other formats including pictures and videos.

The detail required of the self-assessment and the type of online or paper based forms used will be dependent on the type of client the person requiring assistance and support may be. This will depend on many factors including how vulnerable they are perceived to be, how much they are able to exercise autonomy and be considered responsible and trusted adults. People who are considered autonomous and responsible, and in a reasonably safe state of being, and asking for specific assistance and support, assuming they have no issues in the areas they do not mention, are likely to have shorter forms to establish the assistance and support they are requesting. People who are deemed at significant risk or untrustworthy by their circumstances are likely to need to demonstrate all their standard outcomes are being met.

A part of the self-assessment process may include an 'optional' extensive online questionnaire or application form that asks about the individual's impairments, family situation, housing situation, education, employment, hobbies and other issues, difficulties, strength, weaknesses and so on. Because of the potentially invasive nature of the questionnaire but its value to assessors to provide an extensive background to work with, with some kind of payment to individuals who successfully complete the whole questionnaire may be provided. It is important the questionnaire is co-produced with

stakeholders and that some piloting takes place. The notion of payment for cooperation should continue throughout the process.

The purpose of the self assessment is to allow the individual or family to have a prepared document which they can bring to the coproduction assessment process that presents what they perceive to be their desired outcomes and how this can be best delivered in an assistance and support solution. It is not necessarily a document that can be naturally just taken as desired outcome of the assessment but rather a discussion document that can ask questions as well as give answers.

The document should ideally directly or indirectly demonstrate, depending on the understanding ability of the individuals involved, how their outcomes relate to assisting them to fulfil their rights and responsibilities as citizens, as well as fulfilling their social and family roles. With guidance from the assessor, individuals should be encouraged not to be so concerned at this stage about the perceived realities of what can be achieved and rather be a more visionary document of long term desired outcomes.

The time and energy given to the self assessment will depend on the urgency and circumstances in which an assessment has been triggered. If the assessment is born of the crisis assessment, then the first self assessment may be a quick process which can be reviewed at a later stage. During transition points, such as leaving home, plenty of time could be given to this process.

Depending on the outcome on the self-assessment, a number of additional assessments to main process may be arranged with professionals with wheelchairs advisors and dieticians to gain a holistic idea of the range of assistance and support someone may require.

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#### 4.7.3 Co-Produced Outcomes Focus Assessment

The co-produced outcomes focus assessment is the core stage of the whole Supporting Outcomes process and replaces a whole range of assessment processes within social care, education and employment including the Work Capacity Assessment and assessment for Personal Independence Payments (previously Disability Living Allowance).

This is an assessment conducted by the assessor, usually employed by a local specialist team commissioned by the local Support body, along with the individual, their family, any representatives and advocates.

The purpose of the assessment is to co-produce a comprehensive picture of an individual and/or families requirements, how they can be met and by who in a manner that is focused on their outcomes. Some of these outcomes are likely to relate to individual's rights and responsibilities to fulfil family and social roles, as well as making a meaningful contribution to their community and society. Other outcomes may be related to the maintaining of more basic needs like physical health and mental wellbeing.

It is essential the 'claimant' and their families understand the evidence of their outcomes and related need is based of socially based observation and discussion, and it will not require the provision of any form of medical evidence, although health professional may be involved in suggestion specific solutions like wheelchairs, counselling and other therapists.

Those who are used to the current system may find this 'refusal' to consider medical evidence difficult.

Because the right to have outcomes being met does not specific mean it has to met by the state if other solution providers naturally exist in a reasonable manner, those may be exaggerating their difficulties will be exposed by the level and detail of discussion into what exactly their need and how this may be met by an informal solution.

Once the outcomes have been established, the assessment will then focus of how these outcomes can be met, any support that may be needed and from whom. In many cases, the outcomes require actions that can only be conducted by the individuals or families themselves, and this should be recorded, establishing formal recognition of their responsibilities.

Other outcomes may be met by products or services which are outside the responsibility of the local Support body and this should be recorded also, to be followed up by the assessor or individual/families. When the outcomes can be met through assistance and support funding from the local Support body, these should also be recorded.

The outcomes focused assessment will use the self assessment(s) produced as a starting point for the production of the coproduced plan but should not be automatically accepted without question. The assessor has a responsibility to ensure the individuals involved have a full understanding of the consequences of the assessment and have consideration of the issues related to their specific circumstances. The assessor should be confident to challenge individuals and families on why they have chosen their outcomes and why they perceive an outcome can be fulfilled through one way or another.

This is the point where the nature of co-production comes into full play as issues of rights, responsibilities, expectations and value for money come into play. By detailed negotiation, lateral thinking and creativity, a 'win win' solution can be found which offered cost efficiencies to be made which does not compromise on the fulfilment of outcomes. In creating an atmosphere of open discussion rather than conflict, where a degree of trust is established, it will be easier to debate the realities of specific solutions in the manner which is honest and open. It is important for the assessor to have confidence in challenging individuals and families to think about their responsibilities as well as their rights, about what they can do for themselves as well as what they may need support with.

It is important that the assessment is not focused on medical labels or any presumptions based on someone's situation. It is important the assessment is not constrained by any arbitrary notions of fitness or eligibility. The assessment can also not rely on points scoring or focus on level of function to assume eligibility and instead achieve the balancing act in being flexible but fair within national guidelines. By using specifically at the impairment and disability related difficulties. in achieving their outcomes in relation to what may be deemed reason in comparison with non-disabled peers of the same age, occupation and social background. This comparison is what is then used to build a fair and transparent decision, especially in relation to lifestyle outcomes such as hobbies and holidays, as opposed to more basic needs. The notion of fairness and flexibility will mean that two individuals with similar types and levels of impairment may be provided very different levels of assistance and support if the scope of their outcomes or ambitions are very different.

In new or significantly changed circumstances, it may be assessed that some form of enablement and/or empowerment programme is provided to allow individuals and family to progress their circumstances to a new level at which point a further review of the assessment would be needed. It is important to understand that an individual's and families' circumstances will change over time and therefore a number of reviews or reassessments are likely to be needed throughout their 'social care journey', especially if they have had an impairment from birth.

Under ideal circumstances, the assessment will take as long as it needs to and an assessor will meet with the individual and/or family a number of times until everyone is very happy with the result and there is a sense of joint ownership. The reality may make this level of attention difficult, especially if it is a crisis situation, however the principals of the assessment should not be compromised. If individuals or families are unhappy within the decision making process, they should have the right to appeal if they can demonstrate a lack of cooperation. In this way, assessors should not attempt to corrupt the process by taking shortcuts which can now be identified.

It is difficult to provide full and extensive detail of how the assessments would work at this stage because this would require a great amount of consultation with stakeholders, as well as extensive testing, to develop the level of national guidelines required. However, some assessments may result in the need in further specialist assessments for individuals who require specific pieces of equipment, like wheelchairs, or other assistance and support that requires a degree of specialism.

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#### 4.7.4 The assistance and support plan and budget

The draft assistance and support plan or 'application' is the replacement to the social services care plan and other documents, and is a document prepared by the specialist assessment team that details the support funding and other services that would be requested from local Support bodies and what outcome the assistance and support should assist individuals and families to fulfil. The plan should explain all the person's outcomes and how they are going to be met, even if that outcome should not result in a formal assistant and support solution.

The plan should detail the costed making met the direct funding people will receive as well as the actual costs if any services including counseling and impairment specific health services they may receive, so they are aware of the full amount being offered to them. This will help them to better compare what they are receiving in the current system even they are being offered less direct funding and more direct services.

Once the draft plan has been approved by the local support body, with possible amendments, it is then the actual plan and so an active contract between local Support bodies and individuals and/or families as applicants depending on the specific circumstances.

It is important that applicants have the opportunity to check the plan and any assessment reports for accurate and request corrections are made in a manner that builds trust. If a dispute about the plan or report can be resolved between the applicant and the assessor, then there should be a mechanism by a third party to arbitrate.

The plan should not be considered finished until it has answered all of the questions and concerns of the applicant whether formally or informally. People who believe the level of assistance and support is being reduced even if their outcomes are still being met are likely to raise questions on how they are supposed to perform specific tasks, and it is important these are fully answered with specific and personalised responses.

While they may likely to be called for assessments to be recorded because of the toxicity of the current system, the trustworthiness built into this process should make this unwarranted in all but exceptional circumstances as people will have a bigger say in the production of plans and reports.

If an application is unsuccessful, the individual and/or family along with specialist assessment team can resubmit their request so long as there has been either a significant change to the amount required or an update to the reasoning for the requested amount. If individuals and/or families are still unhappy with the decisions made, or the way the assessment has been conducted, there should be a clear and transparent complaints and appeals system that is quick and effective so as to reduce any unnecessary distress. Since the assessment system should be transparent based on reasoning, it should be easy to determine if a decision reached has been fair or not.

It is important that when there are assistance and support requirements that can not be met by the funding available, that it is accurately recorded and explained to the applicant. It is important to understand people have a right to have their assistance and support outcomes being met, but they do not have any right to expect any specific solution.

Where possible, alternative solutions, services or funding streams should be suggested who could assist to meet the requirements. It is also important to understand it is not the role of assistance and support funding to meet all of individual's outcomes but only provide them the assistance and systems to be able to work towards some outcomes they will be solely responsible for, such as passing exams.

The assistance and support plan will be personalised to the specific requirement of individuals and families as described in the assessment. The funding provided may be intended to pay for a number of things including the employment of personal assistants, services like agency care, support to access community opportunities or the provision of equipment, as well as payments for various impairment and disability specific costs that can be used with flexibility for individuals and families to fulfil their desired outcomes.

The assistance and support plan may also detail formal enablement and empowerment programmes involving a whole range of relevant health and social care professionals.

The order in which specific solutions should be considered to meet outcomes should always be mainstream services first, then technology, then personal assistance or other direct service. The decision should be based on the totality of the outcome being met and while value for money has to be considered, it is not about cutting costs in the short term that causes long term problems. There has to be a bias towards people living in the community living as a right and standard expectation, where residential care is seen as a last resort for specific situations.

Impairment and disability costs specific will be costs on the basis of costs an individual or family will experience when performing an activity that a peer who is not impaired will not

experience. It is the belief of this paper that any attempt to average out disability costs would create a level of unfairness that is not compatible with its intentions.

Due to the specific individuality of costs, it is important it is assessed on an individual basis, taking into account reasonable and actual activities. It must also be recognised that while some disability costs can be accurately calculated, others will need to be estimated.

If someone have a lifelong impairment, then the plan should consider the lifetime needs resulting from their outcomes and consider 'investing' in solutions that may be costly in the beginning, but it will be value for money in the long term. This may include setting a younger person up in a fully kitted out smart home that will keep them more independent in the long term. This may include offering funding for driving lessons to reduce a dependency on taxis.

Once the assistance and support plan has been agreed, it is should then be regarded as a legal document between local Support bodies and individuals/families, where each party have roles and responsibilities to fulfil and honour. The accountability of the 'service users' should be in terms of how they have fulfilled their outcomes rather than how they specifically spending the funds made available to them.

The Assistance and Support Plan will be made up of a number of different 'offers' or 'awards'. Offers will be an amount of funding being offered to individuals or families for a specific timeframe, purpose and with specific conditions that may be accepted in full, or a proportion of the total amount or timeframe taken up, changing subtly the relationship between citizen and state. The way offers are split will be at the discretion of individuals and/or families and the assessors and may be in terms of home and work, or mornings and evenings as an example.

Each offer and award should have a specific start date and a provisional end date that is mutually agreed depending on the specific circumstances of the individual or family which may be in terms of weeks, months or even years for life long conditions. Once an offer has been accepted, it will be considered to be an award. Each award can be reviewed separately so that an individual and family do not necessarily have all their eggs in one basket.

The assistance and support plan should also detail what could, should or may happen in relation to safeguarding issues, going into hospital, sick and holiday issues and other matters which that to the roles and responsibilities of both the local Support bodies and service users. If personal assistants are going to be directly employed, the plan should outline what training will be provided to everyone involved and what support will be given.

#### **Recommendations:**

**10) Everyone who requires assistance and/support should receive a assistance and support plan and therefore budget.**

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#### 4.7.5 Implementation

Once the assistance and support plan has been agreed and signed off, the funding from the local Support Bodies can be provided from the date agreed, or an enablement and/or

empowerment process can be implemented. Once support and assistance services or payments are provided, it is important that service users, which would include individuals and families, receive appropriate support from advocates and brokers if that which should be discussed in the plan.

It should be recognised that for new users, having social care assistance and support can be a dramatic change and what appears to be possible on paper, may not feel as possible in real life. During this start period, as well as the support from advocates and brokers, service users should feel that they have access to the person who assessed them to ask questions and check out details by phone or email. Rather than a quick, sharp and invasive process, the relationship between assessor and service user could initially continue until it naturally fades to ensure easy, open and honest communication between user and the local Support bodies reduces fears and anxiety.

Service users should have reassurance that unless specific commitment have been made in the assistance and support plan like the participation in specific employment or education activities, the responsibility to fulfil desired outcomes related to the direction in which a service user's life is taking and is not necessarily about obtaining measurable results. It should be understood that regardless of good intentions, that the realities of how far outcomes can be less and it is about demonstrating a responsibility rather than delivering results.

## 4.8 Review and develop

Clearly once a new service user has fulfilled any enablement and/or empowerment process, they will require a further assessment to determine what assistance and long term support is required if any. However, every service user will need their assistance and support plan to be reviewed on a periodic basis. This should be done before the previous support plan has ended and in plenty of time to allow an easy transition into the new support arrangements.

The period between the reviews will depend on a number of factors including what type of impairment an individual may have, how well the circumstances of the individual and family are, and what is the likelihood that an individual's circumstances is likely to change during that period. For an individual with a progressive condition who is a relevantly new to social care, the period between reviews may be in terms of a few weeks or months and require extensive review. For individuals with long standing impairment who has had social care support for a number of years, the period of review may be in terms of a few years and require a very brief process.

The review process should be personalised to the requirements of the individuals and families involved and should be discussed at the previous assessment. When a service user's conduct over time has clearly demonstrated reliability and consistency, this should be formally recognised and may result in a lighter hand appropriate to reviews. While assistance and support should not be unnecessarily disrupted during the dates of support agreed, the scheduled review process should not prohibit individuals or families from triggering reviews if they feel their circumstances have changed. It should also not prohibit local Support bodies from triggering reviews if they feel funding is not being properly used

or there is significant evidence of a change of circumstances like a long period of unplanned hospitalisation.

Any review should look at challenging users to demonstrate how they have used the funding provided in a fulfilling their desired outcomes and what responsibilities users have taken in this. It could look at how enabled and empowered a service user is and how this can be further developed. The review should acknowledge and embrace any 'mistakes' a service user may have made in implementing the assistance and support plan as a part of their learning and development as active citizens, especially if this is new to them. However, the difference between 'mistakes' with good intent and deliberate fraud, should be understood and appropriate actions should be taken if needed. In allowing service users not to feel threatened by being open and honest, it enables the level of support provided to be duly developed and amended as circumstances require.

It is important people who have formal assistance and support, and continued to be within the system, should have access to named long term case workers who they are able to raise questions and concerns to at any time, and to ask for a review because of a change of circumstances.

## 4.9 Exit Strategies

While it should never be the intention of local Support bodies to reduce the level of support of service users unfairly or unnecessary, it should be accepted and understood by individuals who have the actual possibility of long term functional improvement that some form of exit strategy to reduce the level of assistance and support must be considered. This should not necessarily have a fixed timescale since it needs to be respectful to the circumstances of the service user as well as their emotional readiness to move on. It should balance the responsibility of service users in terms of their improved function with the need to develop sustainable long term inclusion. By gradually reducing the level of assistance and support, it can develop confidence and create enabled and empowered individuals who are able to take up their rights and responsibilities within their community and society at large.

It should also be recognised that there will be a proportion of service users who will need assistance and support throughout their lives and that it may be a waste of resources to attempt any form of exit strategy despite how tempting financial restraints may have it appear. In some impairments like cerebral palsy, while an individual may be enabled or empowered to a specific level of function and feasible activity, local Support bodies can not take into account any claims of medical breakthroughs in their long term planning.

# 5 Implementation issues

## 5.1 Introduction

This final chapter of the paper looks at the potential barriers to fully implementing the proposed assistance and support assessment and allocation system in the real world, and more importantly how these barriers could be overcome. The paper has identified seven central issues that would need to be properly examined to ensure a successful implementation of the system and process. There are clearly a wide range of issues to consider and barriers to overcome, many of which will not become apparent until the process and system is further developed where matters would hopefully become apparent as the implementation of the idea progresses.

In the implementation of the process and system, it is important that all stakeholders are aware that it is a massive and complex exercise, and that there will be bumps on the way. Therefore, it will be important for stakeholders to work together through each stage of the implementation and everyone is allowed to voice their comments and concerns in a constructive and honest manner that would enable joint responsibility. This should avoid the blame game and therefore reduce the fears of potential service users, especially if all concerns are openly addressed and making mistakes are assumed to be part of the course.

## 5.2 Integration of existing funding streams

The first issue to consider is the mechanisms that are needed to merge all existing funding streams to a single assistance and support assessment and allocation system. This must be achieved in a manner that is open, transparent and reduces unnecessarily stress and distressed. Merging a number of funding streams, all of which has different criteria, policies and procedures is going to be a complex and sensitive issue that will need to be handled carefully. Learning from the Individual Budgets Pilot, the commitment of Whitehall must be delivered by Downing Street if this is to happen.

It is proposed that Support England and the local Support bodies are formed at least 12 months before they take full responsibility to funding assistance and support, and that as well as creating the necessary policies and procedures with the help of its stakeholders, their first task would be to collect information on the existing funding arrangements for existing users, includes their disability benefits and personal budgets, and provide individual interim funding statements of the total funding that each user would receive from the local support body and a provisional award ending date, based on a need to stagger initial assessments. Unless the user's assistance and support needs change within this

transition stage, it is the intention that users should receive the same amount they were receiving when the local Support body begins to make payments. The way payments are made including where all or parts of the total payment are paid to and how often will be flexible according to the needs of the user.

An initial assessment is then likely to take place within two years of the start of the new funding arrangements, depending on a number of factors such as the existing stability of previous funding. Any increases of funding from the initial assessment would be immediately offered, while any proposed reduction may be phased in depending on the user's specific situations. The assessment may require the user to consider the funding using very different manner to previously, such as a focus on outcomes, and therefore time and emotional investment is required from the assessor to get this first assessment right, and so reducing problems down the line, making the reviews easier.

There has to be a lot of public information available to make people aware of the transition process, including videos and any other tools that may provide reassurance and to explain the process in terms of providing people with 'super personal budgets'. There will need to be an extensive and voluntary testing, trailing and piloting process, and users to take part should be rewarded for their participation. The process should include local pilots early on to see what unexpected issues will arise including difficulties in the cultural shift.

It is important to recognise and acknowledge the greatest potential barrier to the shift towards a single assessment and allocation system and process will be the changes in culture required by those working within the system. This would require a strong commitment from ministers and senior civil servants, a strong leadership within Support England, and the use of an able and flexible management style that enables professionals' fears and concerns to be addressed.

## 5.3 Portability

The second issue to consider is the portability of funding packages. People with impairments should have the right to choose and be able to move around the country. They should be assured that there is a national eligibility and set of standards, and that when they move, their funding package may be easily transferred from one Support body to another. This means that people will experience a seamless transfer of their payment arrangements, unless the move is raising issues that means the individual wishes to trigger a reassessment. If not, people would receive their current awards until they have their scheduled review exactly as if they have not moved.

There needs to be a comprehensive monitoring system to ensure that there is a continuity of assessment and allocation across the whole country and all local Support bodies, so delivering portability without unexplainable or unpredictable changes in the funding provided, and no one feels there is a postcode lottery, and no one is prevented from moving.

### Recommendations:

**11) Assistance and Support Awards to be portable, relevant to people's specific requirements**

## 5.4 Needs of differing age groups

The third issue is the needs of differing age groups. For the purposes of this paper, there can be seen to be three age groups, which are children and young people, working aged adults and older people. Children and young people may refer to anyone under the age of 18, or in full time education unto the provisional age of 25. Working Aged Adults can be seen as adults 18 - 65 provisionally, or are at an age where they are deemed employable. Older people refer to people who are typically over 65 and who are no longer in full time employment. It must be understood that each age group will have their own broadly typical range of outcomes, needs, desires, expectations and issues that needs to be considered. It is important to note that adult social care policy has previously been centrally basis to the needs of older people, as a political issue, and that this bias needs to end.

For all age groups, the basic outcomes of good physical and mental health, good hygiene etc are likely to be the same although the solutions to reach these outcomes may differ, All age groups should also be regarded as having the same need for human and civil rights, although their responsibilities may differ widely between the age groups, along with the range of high level outcomes.

For children and young people with impairment or disability related issues, the main high-level outcome is most likely going to relate the ability to receive and appreciate a standard education, assumed in this paper to be within a mainstream school environment. The system and process will be related to the practical difficulties in accessing educational opportunities in terms of assistance and support as opposed to any specific adaptations to the teaching methods or syllabus that may be required, since this would remain within the remit of schools and relevant educational authorities.

For working aged adults, the main high-level outcome would be the ability to make meaningful contributions to society, such as paid work and raising a family. Social care has previously tended to focus on basic needs, such as health and hygiene, as opposed to higher level outcomes, and therefore there has been an intention to consider working-aged adults as passive, often to save money. This should not happen in the process, especially since the remit of the funding is wider and so more flexible. Working aged adults should be assumed to have the potential to make a contribution in some way and therefore require assistance and support accordingly.

For older people, the high-level outcome is less uncertain since if they are retired, they will have been regarded as to have made their main contribution to society and therefore earned the right to 'retire'. This should not be assumed to mean that older people can be seen as passive participants in society. The majority of older people have plenty left to contribute to society in terms of a family role, voluntary employment and even paid employment. The stereotyping of older people requiring assistance and support as most being frail and passive must be replaced with a more open minded approach that values of autonomy of older people. The system must also be able to suitably protect anyone who is in a vulnerable position.

## 5.5 Limited Resources

The fourth issue is how the assistance and support assessment and allocation system will manage the fact that the total assistance and support fund will necessarily have clear budgetary limitations especially since there is no proposal for an upper limit as to what one individual or family can receive. It is hoped that the merger of a number of existing structures would reduce the administration of the system and that the long term approach to providing assistance and support would yield future cost savings. Also, it is hoped that the funding of individuals and families will be in parallel with a major investment in accessible infrastructure including public transport and dropped curbs as examples, that would reduce some need for specific assistance and support.

Fairness and value for money will be key elements in ensuring every decision made is as fair and effective as possible, acknowledging that the need for flexibility will create wide variations in what some individuals with similar types and levels will receive because of the different types of outcomes being fulfilled. Individuals and families will be asked to take their share of the responsibility to ensure the assistance and support provided is effective and, more importantly, that they are ready and willing to relinquish assistance and support that is no longer required at the appropriate time, something that is often difficult. This can be supported by making the process and system easy to jump in and out of according to specific needs, that is appropriate for people with unstable and/or unpredictable conditions.

No assistance and support package should be reduced or halted without a reassessment unless it is requested by the service user, and it is proposed there is some incentive scheme for people who halt or reduce their package due to a change of circumstances that protects those who continue to need their assistance and support. There should be peer led working groups within Support England that reviews changes to how specific issues are viewed and therefore funded according to changes in the political, economic, social and technological environment, before going to some form of consultation. That may for example include that the feasibility of driving lessons before funding for a driver can be provided, which would only ever be implemented in their next assessment. In having detailed guidance in this manner, it would retain fairness, value for money and consistency.

The full details of how limited resources will be managed will clearly not become apparent until the process and system is further into its development.

## 5.6 Passporting and Motability

One complexity resulting from the proposal would be its impact on passporting to other services and benefits like a Blue Badge, Bus Pass and Rail Cards. Because Disabled Living Allowance is a label based benefit, it is very easy for it to be used as a passporting

benefit. However, this proposal is more complex and there will not be clear labels that come with the provisional of assistance and support funding. Therefore one way for passporting to occur would be to require assessors to 'pre-approve' special benefits at their discretion based on an understanding of the relevant eligibility criteria of each benefit, on the approval on the local Support bodies, in a manner that is transparent and does not cause controversy or end up being too complex.

In terms of Motability, it should remain an independent service in its current form, except that eligibility for a car will be determined for the car based on need on a wide set of criteria than currently. So, as well as mobility needs, a Motability car may be considered for a range of needs, such as a family who requires a second car due to a child requiring a large number of hospital appointments. Since there will be no upper limit to the amount of funding or services being provided, it means someone who has a car may also have other funding for other mobility needs.

## 5.7 When things goes wrong

The sixth issue is how the process and system will deal with complaints and appeals. Firstly, it is important that is the creation of the assistance and support assessment and allocation system, it is designed to be open, transparent, understandable and flexible, and certainly works to eliminate the 'jobsworth' and inhuman approach does exists within the Department for Work and Pensions, and it associated agencies.

Support England or the local Support body can not assume the worst in people on first sight and must have a positive approach to customer service and the delivery of its assessment and allocation services. It must assume that unforeseen mistakes can occur, through no one's fault or deliberate actions, and therefore be prepared to easily acknowledge errors and correct them quickly and efficiently. At the same time, it must have open and transparent procedures in place to deal with service users who have been proven to have committed fraud or have been consistently uncooperative in their relationship with local support bodies, despite being sensitive to their situation. This means that while there should be plenty of carrot, a stick is needed as a last resort.

Complaints and appeals should be dealt with firstly at a local level and then go up to a regional then national level if people still remain unhappy. All complaints and appeals should be dealt with quickly, effectively and with sensitivity. A complaint may require a home visit to be carried out to determine and support the service user, as well as individuals and a family, to understand what their precise concerns are and how they can be addressed. For appeals, the assessment process should allow a review of their application to clarify matters before it finally reached an independent tribunal system. However, the philosophy of the system is the assessment is not over until the service user is happy, even that just means having the emotional support to understand and accept.

## 5.8 Maintaining Standards

The seventh issue is maintaining standards in terms of the quality and consistency of assessments by the specialist team assessors. The assessment of one individual by another individual is always going to yield some inconsistencies between assessments on a national basis. It is therefore proposed that a national co-produced training framework for all assessors is developed. This would need to include basic training which all assessors must go through, which is designed and delivered with the assistance of disabled and older people, and families. There should also be a feedback and monitoring system for assessors similar to what is used in commercial organisations, so users are systematically asked to rate how the assessment was conducted, so that issues with specific assessors can be identified and resolved.

Service users should also be made aware of what they should be expecting from assessments, so they can easily identify poor assessments and take appropriate actions. The mission statement of Support England and the local Support bodies should include a commitment to achieving and maintaining the highest standards of customer care and professionalism and to work with stakeholders to achieve this. This should include ensuring the customer experience is as good as it can be, ensuring call centres are trained to handle the diverse range of access needs, requirements and enquiries. There should be a single 'Support' website to act as a portal for all matters, enabling users to see the details of their offers, and awards. The aim of the customer service angle of the system should be to become a shining example of good accessibility consider many issues including the use of sign language, easy read, and how to engage with people with non-formal communication. In ensuring good customer service, it is assist in establishing and maintaining faith in the system from its users.

## 5.9 Handling fraud and poor engagement

The eighth issue the process needs to be able to tackle is fraud and poor engagement. It is be a clear mandate of the policy and system to assume people wishes to have assistance and support funding and services are willing to participate in the process and system, and to engage as much as what is asked of them. However, there needs to be clear and transparent policies in place to deal with situations where it is clear that despite several attempts to do so, an individual or family is refusing to cooperate with the process, particularly in terms of reviewing awards.

Offending users should be adequately and suitably warned about the consequences of not engaging with the process and system, namely the potential lost of funding. The approach to engagement should be a big carrot first, and a stick in reserve only it is cannot be avoided.

A culture of 'sanctions' should be avoided at all costs since it is not helpful to the engagement who may begin the process in a fragile emotional state. However, there should be consequences for people who deliberately and knowingly refuse to cooperate with the system. As people begin to become uncooperative they should be clearly informed what will happen if they continue to be and provide every opportunity to return to a state of cooperation.

In terms of handling fraud, the monitoring of assistance and support funding should be seen in terms of how 'on track' an user is in meeting their outcome instead of how

accurately they have spent their money in accordance to the assistance and support plan. However, if it can be established that some is fraudulently misusing funding based on fraud information they have provided, or spending the money in ways that can not be suitably linked to the outcomes they have agreed, then appropriate action to be taken to halt the funding, recover any misused funding, or even take legal action if that is felt necessary depending on the seriousness of the situations.

## 5.10 Getting people on board

The final issue is the challenge of getting and keeping people on board with the fully implemented assessment and allocation system. With the recent political difficulties with the welfare reforms, and other factors, it may be difficult to get all stakeholders confident in such a major change in the way assistance and support is assessed, allocated and delivered. It will require a large scale public awareness and involvement exercise with the support of social care and disability organisations, groups and informal networks, who are in active dialogue during all stages of the implementation. There need to be clear answers on how the process could and should impact individuals and families, and some reassurances and guarantees made where appropriate. The message that the change is not to cut front line costs, but to enhance the assistance and support provided to disabled and older people so they are better included into society.

I hope that this paper will act as a starting point of a public debate that should make the concerns more apparent and therefore able to be managed.

## 5.11 Managing Conflict

A core goal of the new assistance and support system, as well as better providing people with what their specifically need, is to restore faith and trust in the state support for people with impairments and illnesses from the toxic system currently. By having coproduced assessment, the call for video assessments in what is a them and us situation should end and only be desired when people are in very vulnerable situations.

This however does not mean there is not be conflicts between the system and its users, especially if the aspirations of what is proposed is not realised at all levels national and locally. It is hoped that ensuring all stakeholders are actively involved and seen to be involved at all levels of the design, development, implementation, regulation, monitoring, inspection, evaluation and promotion of the system and promotion will be a long way to ensuring trust and even pride in the system for most stakeholders.

There will always be people unhappy with how they believe they have been treated by the system. It is firstly important there is robust appeals and complaints system, so people feel they can raise any concerns they have in a speedy, honest and transparent manner. Some complainants will still find it difficult to understand and accept the outcomes after these routes have taken place, or simply go out to media with uncomprehending concerns rather than making a complaint, causing simplified misinformation to offer. It is vital even that this

point every effort is made to try to resolve concerns and reach a meaningful understanding.

If a misunderstanding continues to be created in the media, a specialist national team works with the media to attempt to explain and convey the facts of the situation, including some elements about the concerns, acknowledging when errors have occurred, to ensure a balanced view is considered for the welfare of all users who are become worried by misinformation.

## 5.12 Peer Support

It is clear that many users of the assistance and support system will benefit from peer support, but it is important that it is the right kind of peer support as people will desire and need differing levels and types of support. There should be a variety of peer support options available at a national and local level which any user may access at any time. These may include face to face meetings, buddying systems, mentoring, online groups and so on.

## 5.13 User Involvement

It is vital there is genuine and meaningful user involvement in the design, implementation and evaluation of the system and process at all levels nationally and locally. This involvement must be sensitive to the diversity of impairment and illnesses as well as the diversity of experiences and backgrounds of users, where no one user and user-led group is seen or used as the representatives of other users, where every contribution is valued as an opinion to be considered amongst others.

The current network is user-led organisation in the disability and independent living movement fail to engage with or support the voices of the diversity of users that the system needs to be involved, as well as being unable to accept the new values the system will uphold. The system will see users as being very important in shaping the system and indeed their own lives but will not deem users to be the ultimate experts and beyond challenge, as they can be wrong like anyone else.

This means there needs to be new and innovated ways of recruiting to the many involvement activities the system will create and ensure they are duly paid and valued for their time and commitment in ensure the system works along with other stakeholders.

# 6 Conclusion

The intention of this document is to promote discussion and debate on the complex issue of defining, assessing and implementing a new assistance and support assessment and allocation system for disabled people.

The Supporting Outcomes assistance and ensure concept, system and process is a reflection of current and new thinking and issues in a manner that provides a comprehensive pathway in establishing and implementing key concepts to meet current and future expectations of all stakeholders.

It is important to understand the Supporting Outcomes concept does not try to favour potential service users or potential funders, but rather attempts to match the requirements of both parties to develop a system which is universally fair. Only in this way can an assistance and support assessment and allocation system for anyone with impairment specific issues be fair. In advocating an outcomes focus assessment system that is based on rights and responsibility, it is matching the development of adult social care from the 1948 National Assistance Act to current and future requirements.

The next stage of implementing this proposal would be to produce greater research into its implications on areas such as the cost efficiencies it could produce, the costs of implementation, the impact on various groups and so on. This will enable a 'white paper' to be produced for a public consultation by the Government or as any other policy consultation.

This is a working document that will develop and expand over time as it is used by its partners and others. All feedback is positively encouraged and can be provided below or by contacting Simon Stevens on [simon@simonstevens.com](mailto:simon@simonstevens.com)

# 7 Further Reading

<http://disabilityrightsuk.blogspot.co.uk/2012/05/disability-rights-in-need-of.html>

# Appendix A: Basic rights

## A. Physical Health

- A1 To be free of infection
- A2 To be free of physical injury
- A3 To be managing long term conditions effectively
- A4 To have regular check-ups
- A5 To minimise levels of pain
- A6 To have access to appropriate medications
- A7 To have access to appropriate therapies and treatments
- A8 To be physically fit and healthy as possible
  - A8.1 To take part in sport on a regular basis
- A9 To be drinking responsibly
- A10 To have be at an ideal weight
- A11 To eat well with a good diet
  - A11.1 To eat an appropriate amount of food each day
- A12 To sleep well

## B. Mental Health

- B1 To be free from despair and distress
- B2 To be as mentally well as possible
- B3 To be managing long term mental health issues
- B4 To have minimum stress
  - B4.1 To have access to leisure opportunities
- B5 To have confidence
- B6 To feel safe
- B7 To manage moods effectively
- B8 To feel positive

## C. Personal Care

- C1 To dress and undress
- C2 To manage continence
  - C2.1 To be able to go to toilet as needed
  - C2.2 To be able to use continence aids like nappies if needed
- C3 To be personally clean
  - C3.1 To have a method to be clean every day
- C4 To have good dental hygiene
  - C4.1 To have a method of cleaning teeth
- C5 To be personally groomed
  - C5.1 To be able to arrange hair
  - C5.2 To be able to apply make up
  - C5.3 To be clean shaven
  - C5.4 To have tidy finger nails
  - C5.5 To have tidy toe nails
- C6 To consume food and drink
  - C6.1 To be able to feed or be fed

C6.2 To be able to have a drink

D. Communication

- D1 To be able to talk to people
- D2 To be able to write/email people
- D3 To be able to read printed material

E. Personal mobility

- E1 To be able to move around indoors
- E2 To be able to use travel locally

F. Daily living

- F1 To prepare meals
  - F1.1 To be able to cook and prepare food
- F2 To have clean clothes and bedding
  - F2.1 To be able to wash clothes
  - F2.2 To be able to iron clothes
- F3 To have a clean and tidy home
  - F3.1 To be able to clean and tidy
  - F3.2 To be able to Hoover
- F4 To shop for groceries
- F5 To manage personal monies
  - F5.1 To access banking services

G. **Housing**

- G1 To have a safe place to sleep
  - G1.1 To have something to sleep in
  - G1.2 To have a safe environment to sleep at
- G2 To have somewhere to get clean
  - G2.1 To have a safe place to get clean
  - G2.2 To have facilities to clean at
  - G2.3 To have consumables to clean with
- G3 To have somewhere safe to go to the toilet
  - G3.1 To have a place to go to the toilet
  - G3.2 To have facilities to use
  - G3.3 To have consumables needed
- G4 To have somewhere to prepare and consume food
  - G4.1 To have a place to go to the cook
  - G4.2 To have facilities to use
  - G4.3 To have consumables needed
- G5 To have somewhere to rest
  - G5.1 To have a place to go to the rest
  - G5.2 To have facilities to use
- G6 To have personal mobility at home
  - G6.1 To have access to all parts of the home
- G7 To feel safe in the home
  - G7.1 To have a home that is secure
- G8 To have a home environment which meets lifestyle needs and financial standing
- G9 To have ability to stay warm
  - G9.1 Access to heating
- G10 To have the services needed to run a home

- G10.1 Electric
- G10.2 Gas
- G10.3 Water
- G10.4 Waste

#### H. **Financial Needs**

- H1 To be able to afford to live
  - H1.1 To be able to pay for food
  - H1.2 To be able to pay for housing
  - H1.3 To be able to pay for energy
  - H1.4 To be able to pay for health
  - H1.5 To be able to pay for family responsibility
- H2 To pay taxes
- H3 To develop savings
- H4 To be able to spend available money

#### I. **Transport**

- I1 To have access to immediate neighbourhood
- I2 To have access to nearest major commercial centre
- I3 To have access to nearest administrative centre
- I4 To be able to get to the nearest town/city centre
- I5 To have access to family where appropriate
- I6 To have equal access to national and international travel

#### J. **Family Life**

- J1 To have appropriate sexual relationships
  - J1.1 To have a one night stand
  - J1.2 To have a sexual partner
- J2 To have access to immediate family
  - J2.1 To know mother, father and siblings
- J3 To have access to active extended family
  - J3.1 To know and visit extended family
- J4 To be in a long term relationship
- J5 To be married
  - J5.1 To be able to marry someone loved
- J6 To be a responsible parent
  - J6.1 To have a child in a loving environment
- J7 To engage in family life
  - J7.1 To attend weddings, funerals and family celebrations
- J8 To be an active grandparent
  - J8.1 To support children to have their own children
- J9 To be an active family supporter
  - J9.1 To support other family members with difficulties

#### K. **Personal safety and Justice**

- K1 To feel and be safe at all times
- K2 To be free from bullying and intimidation
- K3 To be free from torture
- K4 To have access to policing
- K5 To have access to justice

K6 To have good prisons

**L. Learning and Skills**

- L1 To have a basic education
  - L1.1 To be able to read and write
  - L1.2 To understand numbers
- L2 To complete further and higher education opportunities
  - L2.1 To have A-levels
  - L2.2 To have a degree
- L3 To complete vocational training
  - L3.1 To have relevant skills for a specific job
- L4 To have access to professional development
  - L4.1 To have training to develop my career
- L5 To have access to informal learning
  - L5.1 To develop my lived experiences
  - L5.2 To develop my world wiseness

**M. Employment**

- M1 To have access to job-related training
- M2 To find an appropriate job
- M3 To be in paid employment
- M4 To be ready and prepared for retirement
- M5 To continue to develop my career

**N. Expression**

- N1 To have free responsibility speech
- N2 To pursue creative endeavours

**O. Lifestyle**

- O1 To choose and practice religious activity
- O2 To decide sexual orientation
- O3 To decide gender identity

**P. Community Involvement**

- P1 To access volunteering opportunities in my community
- P2 To do sport regularly
- P3 To make to political contribution
  - P3.1 To become a councillor or MP
  - P3.2 To be involved in Political parties
- P4 Participation in geographic and issue based community activities
  - P4.1 To be committee member of group and society

**Q. Autonomy**

- Q1 To be able to make decisions about personal situation
- Q2 To be able to take responsibility for own actions
- Q3 To be able to choose your housing situation
  - Q3.1 To be able to choose who you live with
  - Q3.2 To be able to choose the location of your home

**R. Personal gratification**

- R1 To feel a pure sure

- R2 To feel happy
- R3 To feel love
- R4 To feel whole
- R5 To feel fulfil