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PERSONAL BUDGETS

A NEW WAY TO FINANCE DISABILITY SERVICES

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I. Introduction

The move towards self-determination and person-centeredness of care and support provision in the social services sector is one of most fundamental policy and practice changes of recent years. In the large majority of European countries, governments, service providers and users have supported and advocated those changes with the intention of ensuring that care and support become more tailored to individuals and their particular needs and preferences. Some countries began this process from a direct service model – where public authorities decide how to allocate public spending on health social care services – to a model based on personal budgets, where resources are in the individuals' hands. Other countries have introduced personal budgets but are still testing how to definitely move towards an individualised system of funding.

While there are different personal budget models, the central idea behind each is to place the individual, who is receiving a certain amount of money, at the centre of the process of identifying needs and making choice over the services and supports he needs. By comparison, the dominant model placed some restrictions on how the money granted could be spent and spending would often be audited carefully.

The different applications of the personal budget approach must be understood in the particular cultural and political context of a country. Most programmes aim to promote the personalisation of health and social care services, to reduce overall costs to health and social care, to promote independent living and/or improve the family's capacity to take on caring responsibilities. Other programmes aim to reduce the fragmentation of services in remote, rural areas, or to stimulate private sector provision of care services. A further complication in comparing the different personal budget models lies in the fact that services are "packaged" and financed in different ways. For instance in some countries people with on-going healthcare needs might be eligible for national health services whereas in others, such as Germany, those aspects of care would fall within long-term care packages provided by long-term care insurance.

In this paper we will define the personal budget by considering the eligibility criteria, target audiences, availability and usability of the budget. This will also cover people with disabilities. We will present some country cases where personal budget models have been applied with positive results. In the second part of the paper we will focus on the impact of personal budgets on service providers and take a closer look at the opinions of different European stakeholders on personal budgets.

II. Defining the personal budget

Personal budgets mean that people in need of services receive a certain amount of money which they can spend on services and support to meet their expressed needs. Usually those needs are assessed by health and social care professionals in consultation with the service user. The amount of personal budget to be granted is based on this assessment. The idea is that "money follows the persons' needs"[1] to empower individuals to have increased personal responsibility, independence, capability and resilience through the choice and control of services, independently from how the provision of personal budget is organised. Personal budgets make it possible for people to decide for themselves where, when, how and from whom they receive support. From being a passive receiver of care, they become an active participant in the process of deciding about their care needs: as a purchaser, as a consumer and even as an employer. The intention is thus to offer people more chances for self-determination and to give them sufficient independence so that they can play their roles as equal citizens.

- ***Different models of personal budgets***

Personal budget delivery models differ in the levels of choice and control assigned to service users, professionals, service providers and public authorities. Although personal budget schemes vary considerably in areas such as eligibility criteria, services covered and benefit limits, there are some common characteristics all based on the idea of individualised support. Services determined by the person are often provided on a one-to-one basis[2], are flexible and responsive to the person's changing needs and preferences, and crucially they allow a high degree of specificity.

Comparative studies examining the similarities and differences of personal budget models in social care show that there are two main models:

1) *Professionally monitored/assisted model*: personal budget holders receive assistance from care managers, professionals or brokers to access funding and monitor the services provision according to an approved care plan. Service users can leave it up to a state agency, a third organisation (this can be a service provider), a professional or a

[1] Janet Carter Arnand and others, "The transition to Personal Budgets for People with Disabilities: a Review of Practice in Specified jurisdictions", A National Disability Authority Working Paper, November 2012.
[2] More often services are provided to groups of clients, especially training and vocational services that aim to develop essential work and clients' life skills and develop their full potential.

"broker agency"[3] with the responsibility of organising and paying for services, but always by choosing how and who will provide services.

2) *Service user directed model*: service users can receive their personal budget as a direct payment (cash or voucher) with which they can employ social workers or family members and commission services for themselves. In this way, service users take on the responsibility for paying wages, establishing employment contracts and organising their care needs. Often "brokerage services" are available to give guidance on budgeting and sourcing services. This service is usually provided by professionals or through existing organisations.

- ***Who can benefit from personal budgets?***

In principle, personal budgets can be used by any person in need and any person with disabilities, including illness, chronic health conditions, intellectual disability or sensory impairment, but in some countries age brackets can have a limiting effect on certain groups and/or disabilities. The Netherlands and the United Kingdom are the countries with the highest number of personal budget holders[4]. In those two countries many different groups (people in need of services) are considered eligible to receive personal budget. In the Netherlands there is neither a minimum nor maximum age limit to receive a personal budget, which means that the agreement also applies to children and elderly people. For people with physical or sensory impairments, there are many access systems which help services users gain a personal budget after having received a professional assessment. Moreover, personal budgets can also be granted to people with intellectual disabilities and mental health problems if they live in institutionalised settings, such as communities, which are often owned and organised by service providers. Service users can choose their own support workers.

In the United Kingdom, disabled people can be budget holders from the age of 16, and parents that are responsible for their disabled child can also apply for a personal budget. Care givers working for disabled people can make use of a budget to support themselves, for example with tasks like domestic chores or with training. Elderly people, intellectually disabled people, people with mental health problems, people who are in a recovery or rehabilitation

[3] Brokerage refers to the information, support and guidance people may need to enable them to successfully plan, arrange and manage their support and services.

[4] In United Kingdom more than 400.000 people have access to a personal budget. As March 2012, about 53% of service users were signed up to personal budget scheme. Press release of Association Directors of Adult Social Services (20 June 2012), http://www.adass.org.uk/index.php?option=com_content&view=article&id=816

process (for a short period of time) and people with a sensory disability can all apply for personal budget. Physically disabled people and people with a sensory disability constitute the largest group on average, whereas the smallest group comprises those with mental health problems. Personal budgets can also be granted to people with learning disabilities, but in these cases parents or third parties manage the budget. People can also make an appeal to a "circle of friends" for their budget management - a network of family members or other people closely related to the budget holder. As we will see later in this paper, people in the United Kingdom with long-term care needs are also eligible to receive personal budgets. This is the result of social care reform (2007) and a piloting period (2009), when personal budget schemes were applied to the National Health Service (NHS), thereby greatly expanding the eligibility criteria.

Likewise in Germany there are no maximum limits of age or type of disabilities defined when allocating personal budgets. All those in need of services are entitled to apply, including those that are "frequently or to a considerable extent" in need of care because of physical, psychological or mental illness or disability during their daily activities or for a period of at least six months (this includes children and elderly people). Beneficiaries of German long-term care insurance living at home can choose to receive cash payment or care in kind services.

In other countries, such as in Scandinavia, eligibility criteria are more selective. In Sweden, where legislation provides a voucher system for a certain amount of care hours, people with disabilities who acquired their disability after the age of 65 are not eligible to receive personal budgets, as well people with disabilities living in group housing or a residential facility. In Norway and Finland the number of people with intellectual disabilities receiving personal budgets is very low. This is unsurprising if we consider that for a few years Finnish legislation has provided new possibilities to purchase assistance via organisations that can tender for a contract with local authorities, thus offering a new range of opportunities for people with learning disabilities. In only one particular country – Denmark – people with physical disability can obtain a personal budget, whereas people with mental health problems are not eligible to receive the subsidies.

However this situation is likely to change in the coming years. The open ended character of personal budgets and the broad eligibility criteria (as in the Netherlands, for instance) are no longer compatible with the current critical economic context faced by EU member states. The austerity programmes announced and implemented by EU governments have led to substantial restrictions on access to personal budget schemes by tightening the eligibility criteria and the composition of services packages that budget holders can purchase.

- ***What type of services can be purchased with personal budgets?***

Service users, if allowed by the system in place, can use personal budgets to purchase different types of services:

a) Those related to social care service, e.g. home care, day care, personal assistant;
b) Well-being-related services: complementary therapy, leisure activities and equipment;
c) Therapy and nursing services such as nurse and physiotherapy visits;
d) Other health services like specialist long-term care services.

Some limitations can apply on how the budget is used. These are closely linked to the national/local implementation of the programme and to the individuals' attitude around purchasing mainstream services or innovative and non-traditional supports. In the Netherlands, personal budgets must be used to purchase care-related services: home care, personal care, nursing care, support services such as day time activities, active guidance and temporary accommodation (respite for short holidays/weekends). Personal budgets cannot be used for alternative or medical treatments, a restriction also in foreseen in the United Kingdom, where personal budgets, beside conventional treatments, currently include alternative therapies and medicines, such as reflexology, reiki and aromatherapy, and well-being services and related technology.

In Germany personal budget holders have a wide choice in choosing the services they need. They are entitled to spend their money in services supporting the integration and participation in community life, such as workplace assistance, transport, nursing, leisure activities, living costs to support assisted living, therapy costs, support equipment, etc.; and services provided by health and care insurance, although only when needed regularly and on a supplementary basis.

Countries that are currently testing the application of personal budget schemes as a new way to finance health and social services are allowing service users to spend their budget to employ personal assistants, reimburse family members providing informal care (Austria) or purchase traditional care services from a choice of providers.

- ***Level of service users' control on personal budgets***

The main differences noticed between the various applications of personal budgets lies in the degree of user choice and control on the money received. Most of the programmes allow service users to use their budget to employ their own carers (family members) or to purchase

care services from providers. In some cases budget holders are limited in allocating their money. For example, in France the budget can be used to purchase a specific care package, whereas in Finland the choice of service provider is limited to a list of approved providers. In other countries where there are no restrictions on how to use the budget, often the expenditure is linked to identified outcomes (United Kingdom and Netherlands) or list of services.

At the heart of the comparison between personal budget schemes lies the impact that they have on the level of autonomy and degree of choice available to the user. How much self-determination is available to the user is assessed according to his/her capacity to use the budget by choosing between concrete alternatives, and to the "programmatic involvement" - the degree to which the budget provider (public authorities/agency or service providers) is involved in the management of the process. In some countries personal budgets are granted on the basis of an assistance plan that requires approval. Here, expenditure for the purchase of planned care services has to be authorised and the expenditures accounted for. By comparison, other countries require no accounting mechanisms but only periodical reviews to check that personal budget holders receive adequate care and services. If care is deemed insufficient, the cash allowance is withdrawn in favour of services provided by a home care agency.

In the Netherlands, as well as in Germany, people receiving personal budgets can choose between care in kind, a direct payment, or a combination of both. If service users decide to obtain personal budgets as care in kind, they will receive services through standard providers in term of an allocation of hours. In the process of organising care, service users can ask to be supported by an organisation or a professional and allocate part of the personal budget to pay for this mediation service. Personal budget holders can outsource the entire control of their budget to a third part such as a specialised organisation (this can be a service provider) or a legal representative.

Studies on the impact of personal budgets on service users' lives show that personal budgets are "generally welcomed by service users because they offered more opportunity for choice and control over support arrangements than conventional social care arrangements"[5]. Personal budgets bring positive outcomes in terms of patient satisfaction, feelings of wellbeing, and quality of life for the majority of users. By contrast, evidence is lacking to demonstrate that personal budgets have a direct and positive impact on health outcomes, in other words an improvement in users' physical and clinical condition.

[5] The IBSEN project (2008) National evaluation of the Individual Budges Pilot Projects, http://php.york.ac.uk/inst/spru/research/summs/ibsen.php

III. Country-case-studies

The political and legal context has a strong impact on the organisation of social services provision at national/local level. In most cases, public authorities are influenced in their choice on how to provide health and social care services by the need to create a stronger and more stratified and competitive market, and by the need to reduce overall public spending. At the same time, the increasing pressure of civil society's call for more concrete efforts to enforce the principle of self-determination for all people[6], as expressed in the Universal Declaration of Human Rights and in the UN Convention on the Rights of Persons with Disabilities, has had – and is still having – a considerable impact in reforming social services provision systems.

The majority of EU member states appear to have developed mainstream policy where there are clear statements supporting options for independent living, including direct payment schemes (Netherlands, Ireland, United Kingdom). Some countries have developed individual pieces of legislation which articulate aspects of support for independent living, such as the right to personal assistance and to personal budgets (Germany, Sweden, Italy, and Spain).

Although some EU countries are not listed here, it does not mean that personal budgets are not being tested, but only that more empirical findings need to be published. In countries where personal budgets are in a testing phase, such as Spain, the Czech Republic and Slovenia, traditional patterns of support are implemented, including the payment of a disability allowance or the provision, either by the State, the local authorities, or the municipalities, of support services and/or personal assistants. Nevertheless empirical examples are found from some countries, such as the Netherlands, Germany and the United Kingdom, where personal budget schemes were introduced at the end of the 90s. The schemes in these countries have turned out to be successful mechanisms with a positive impact on the quality of life of services users, including people with disabilities.

The following overview on how those three EU countries have implemented personal budget programmes helps to explain the key factors of successful schemes and the implications for professionals, service providers and public authorities, especially in time of crisis.

[6] Article 3 of the UN Convention on the Rights of Persons with Disabilities lists as one of the general principles the "respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independences of persons".

- ***The Dutch experience: a pioneering way to empower people with disabilities***

In the 1995 the Netherlands instituted a programme based on social insurance in which people could choose to receive a personal budget rather than services. According to the Exceptional Medical Expenses Act and the Provisions Act for Disabled and Elderly People, people suffering from disability, a chronic illness, psychiatric problems or age-related impairments can receive a sum of money to purchase various kinds of services and support. Their personal situation is built in to the decision-making process of granting the personal budget or other assistance means, such as the modification/renovation of the home-residence. Applications are made by contacting the Centre for Needs Assessment (Centrum Indicatiestelling Zorg – CIZ) in the individual's place of residence. As of 1st of January 2007 the home care function of the personal budget has been transferred from the AWBZ (Algemene Wet en Bijzondere Ziektekosten, covering general law and specific medical expenses) to the WMO (Wet Maatschappelijke Ondersteuning, covering law concerning social support). This means that the municipalities are directly responsible for the provision of home care as well as support equipment such as wheelchairs, transportation facilities or housing adjustments. The municipalities can freely decide on the regulations to be made and the facilities to be provided.

One important feature of the personal budget delivery model developed in the Netherlands is the possibility for many different groups of service users to be considered eligible to receive personal budgets. All those identified as needing treatment can opt for a personal budget, including intellectually disabled people or people with mental health problems. Those applying for personal budgets must complete a needs assessment and submit a care agreement. The needs assessment does not strictly indicate which services the user should purchase but does oblige him/her to justify his choice in according to his/her needs assessment and submitted care agreement. To support people claiming the budget, the governments instituted the Sociale Verzekerings Bank (social insurance bank) to manage all administrative matters.

Evidence shows that service users often employ family members as care givers (defined as such if they have a family relation until the second degree and/or they live in the same house and if they care for someone for longer than three months). Service users preferred this choice at the initial phase when personal budgets were introduced for the first time. They felt more confident in purchasing care services from "well known" individuals such as family members and/or friends.

Since 2001 people have been able to choose between the different forms of personal budget delivery and combine those according to personal needs. The existence of concrete and

sufficient alternatives for service users when organising their care services has facilitated the application of a personal budget system in the country. And people with disabilities and other services users do not face any ambiguity about how to spend their personal budgets.

However the increasing number of personal budget holders in recent years (between 2002 and 2010 the number of personal budget holders increased 10-fold, from 13000 to 130000, while spending increased on average by 23% a year from 0.4 billion € to 2.2 billion € in the same period)[7] and the current economic difficulties have led the Dutch government to review the implementation of the personal budget scheme by approving substantial changes. By January 2014, only those who would otherwise have to move into care or a nursing home will be able to keep their personal budget or apply for one. People who are no longer eligible for a personal budget but need care that cannot be provided by regular provider organisations can apply for funds through the "reimbursement rule for personal care"[8]. The new mechanism allows people to keep tailored services by choosing their own care providers, but financial limits are clearly defined by the authorities. The effects of this new funding system on service users are unclear, but the government's expectation is that the numbers of people applying for personal budgets will diminish.

- ***Reform of the consumer direct care in Germany***

In Germany personal budgets for care-related services were introduced in 1995, and extended to people with mental disabilities in 2008, after a piloting period, with the aim to help the latter to better manage their care. Prior to 2008, the allocation of personal budgets for people with mental illness, mostly delivered as care in kind or vouchers, was made at the discretion of the public authority/agency charged with service delivery. Personal budgets (Tägerübergreifendes Persönliches Budget), as introduced in 2008, have allowed people with disabilities to have direct contact with one public authority/agency and apply for a budget to cover all the different services they need (care-related, health-related, rehabilitation services).

To apply for a personal budget service users can contact whichever authorities is involved: care insurance, pension insurance, youth service, social service, integration bureau, employment agencies and the regional service bureaus. This contact is independent of the services they intend to purchase. Budget holders only have one contact person, even when they

[7] E. van Ginneken, P. Groenewegen, M. McKee; Personal healthcare budgets: what can England learn from the Natherlands? British Medical Journal: 2012, 344 (e1383).
[8] *Idem.*

receive money from different authorities. After the application process, service users should receive an answer from all the concerned authorities/agencies and attend an interview to finalise the needs assessment. Once the assistance plan has been confirmed by both parties the users will receive their personal budgets, accompanied by a signed agreement which includes the benefit and compensations the service users are entitled to.

This system did not introduce any additional grant, but represented a new form of payment for social benefits that made the provision of care services more flexible. After an initial testing phase this personal budget model became the main budgeting system to support people with disabilities. And initial pilots suggest that people with disabilities receiving support did feel more empowered in the sense that they (and their organisations) have had an impact in campaigning to have a stronger control on services' choice, independent living and changing laws.

Evidence shows that the involvement of service users and their families at every stage of decision making and need planning is important to devise an appropriate assistance plan. Such plans include the number of hours and type of support or services, and the ways in which the person in need wishes to receive support. If the assessment plan is accepted, they will receive a personal budget according to the expressed needs, in accordance with the responsibilities of the concerned authorities/agencies and within the legal boundaries regulating the provision of services. This means that if the personal budget includes services delivered by social welfare (for which local authorities are responsible), the public authorities will decide the level of the budget to be granted to the service user. The main consequence of this social care legislation is that the vast majority of personal budget holders are dependent on health and social care services provided by the social welfare.

Personal budget holders can choose how to receive the services purchased. They can receive them from a social care provider at the price that the provider decides, choose personal assistance, or combine both solutions. In the case they prefer to receive personal assistance, the public authority determines the budget on the basis of the hourly/wages fixed for personal assistance in the place of residence. Service users can also opt for the public authority to make direct payments to the care provider. While local authorities provide help with the management of personal budgets, this service has been criticised for its strict limitation in targeting groups. There are, for instance, counseling services which only apply to people with learning disabilities, such as the "Lebenshilfe" service.

- ***United Kingdom: from direct payments to personal health budgets***

Unlike the Netherlands, the United Kingdom has a long tradition of direct payment schemes but a slow take-up process of personal budgets. The initial idea of direct payments was developed by the disabled peoples' movement in the 1980s to support their independence with state. Direct payments were only introduced in 1997 with the Community Care (Direct Payments) Act of 1996, which allowed working age disabled adults to receive direct payments from the local authority to fulfill their care needs. In 2000 older people were declared eligible for direct payments, and in 2001 the legislation was extended to include parents of disabled children and care givers. In 2003, through the Health and Social Care Act 2001, direct payments were extended to people with disabilities considered as "willing and able" to manage direct payments, with or without assistance. It was only in 2009 that people with mental health problems were considered eligible to receive direct payments.

Direct payments, considered as a form of personal budget delivery, are given as local council cash payments for people who have been assessed as needing help from social care services and who would like to arrange their own care and support services. The amount is decided by the local authority based on a needs assessment and generally corresponds to the reasonable cost of the service that would otherwise be provided by the authority. The recipient is free to purchase additional or better quality services if he wishes to do so, but he must use his own resources. In the case where payment is estimated to be insufficient to purchase the services to meet the assessed needs, the service user has the possibility to initiate a complaints procedure.

The service user can use the direct payment to make independent purchases of services to meet short term needs, for example to employ personal home care assistance after a stay in hospital, or for non-residential care services which enable individuals to experiment with independent living. Direct payments cannot be used to cover long term care for care homes, but only for short stays not exceeding a period of four consecutive weeks in a one year period. Service users receiving direct payments cannot use these benefit to employ close relatives to deliver services.

In 2007 the UK government, needed to reduce public spending in social services, promoted personal budgets as "the route to transforming social care and achieving greater choice and control for service users"[9]. As part of the social care reforms, the government document "Putting

[9] Peter Beresford, Social care: from personal budgets to a person-centred policy and practice, Open Democracy, 30 April 2013.

People First" and the white paper "Equity and Excellence" initiated a move towards the "personalisation" of support and the centeredness of individuals in the service delivery system. As result of this reform local authorities will be expected to have made "significant steps towards reshaping and redesign of their adult social care services"[10]. As of August 2009, around 14,000 people (93,000 if you include direct payments) were holding personal budgets in 60 local authority areas, and around 500 people per month were in the process of making the transition[11].

In 2009 personal budgets were piloted by the National Health Service (NHS), allowing people with disabilities to have a wider choice not only over social care services but also over health and clinical services. By introducing personal budgets from the offset in the National Health Service, the UK government differentiated itself from most other EU countries, where self-determination of people in need has been initiated in long-term care with a limited range of clinical services like nursing care.

An evaluation of the pilot programme showed positive results in terms of service user satisfaction, improvements in well-being and in health outcomes. In the meantime, it revealed an issue related to the dividing line between health and social care services. While these services are funded differently, evidence found that many people receiving personal budgets for social care used the money to purchase a range of services traditionally defined as health care. Subsequently, a number of objections have been raised about the shifting of financial resources and about the quality of services delivered. Professionals employed by local authorities and the NHS are trained to specific standards and subject to strong regulation and monitoring. In social care there has been significant debate about the employment by service users of untrained personal assistants, and the terms and conditions of employment of such assistants. And in the health field there are concerns around individuals choosing to purchase services from untrained and potentially dangerous practitioners of alternative therapies. Ultimately, giving choice and responsibility to individuals and letting go some professional control inevitably entails some risk.

The implementation of personal health budgets requires local authorities to implement a monitoring system of service quality, as a means of ensure safety and maintain minimum standards. At the same time, they are called to encourage existing service providers to innovate the market and not leave personal health budget holders with limited options.

[10] *Idem.*
[11] ACEVO Association of Chief Executive of Voluntary Organisations, An Introduction to personal budges. 2010.

IV. Impact of personal budget on service providers

Service providers have supported the process of personalisation of services and the introduction of personal budgets. Providers defend the idea that personal budgets facilitate opportunities for personal development and greater independence for people with disabilities through increased responsibility, flexibility and choice. Personal budgets have pioneered independent living, enabling people with disabilities to move out of institutions, have more control over their life and contribute to a better quality of life with real empowerment and higher satisfaction. However, there are concerns that personal budget schemes can reduce the control for some service users, for instance those without the ability or capacity to manage personal budgets, unless support is in place to facilitate their access to and management of this type of funding.

The successful introduction of personal budgets depends on the positive response of existing service providers to adopt a new care philosophy. This requires moving from professionally-driven to person-centred models of provision, as well as the ability to create new types of services that can better respond to service users' demands. People using personal budgets do indeed look for new/different types of support. Evidence shows that they gradually move away from traditional services and become more creative in designing their own care. At the same time, budget holders who continue to use traditional services express the desire to receive more individualised care. The introduction of personal budgets can therefore increase the demand for personal assistants, as more people move out of residential care or request specific advocacy services to support how they spend their personal budgets. There is also a growth in leisure services like fitness training, gyms, physiotherapy and yoga classes, in accessing services for personal development and in purchasing assistive technologies.

The first challenge faced by service providers is thus to understand how the demand for social services will change for people receiving personal budgets. Providers have to adapt their services provision by defining new care packages which are more flexible and comprehensive. For instance in the provision of domiciliary, care providers can offer a greater range of services like nail cutting, can accompany service users on day trips or with shopping, offer telecare services or provide support for home modifications. In this process it is important that providers accurately define what they offer and how much it will cost in order to respond to the demands of personal budget holders who want to know exactly what they are getting for the money they are spending. Providers will need to negotiate directly with clients and deliver administrative services linked to the invoicing and credit control for the services provided. In line with these

back office functions, it is advantageous for service providers to assume a brokerage role and to support service users in designing their care services plan or in learning payroll and employment rules[12]. Moreover providers could develop advocacy services and assist personal budget holders in assessing their needs, planning their care and managing the purchase of services. These two services are crucial in the transitional period where temporary gaps in the supply of certain services are likely to limit some personal budget holders' access to appropriate care services.

The introduction of personal budget models has implications which relate to the change in relationship between service users and providers, one which is much more direct and empowering. As personal budget holders become direct employers or clients they can raise concerns about the quality of the services, and if they are not satisfied they are free to choose to take their business elsewhere. To maintain competitive high quality services, providers need to invest in staff training and development, such as risk assessment training or training on how to meet the needs of particular user groups. Moreover they need to adopt a values-based recruitment method in order to ensure that staff have the appropriate mindset and attitude to deliver personalised services. Finally, professionals are required to build a collaborative relationship with service users who express their needs and expected outcomes[13].

In this phase, it is crucial for service providers to receive regular updates and feedback from public authorities on their progress and plans relating to personal budgets. The primary issues are related to the criteria used in approving personal budgets, the prices of services that in some countries are changing an hourly basis, or in relation to monitoring schemes put in place to avoid or reduce fraud of personal budgets. The discussion about which services can be purchased with personal budgets, as we have seen before, differs between countries and becomes more important in times of crisis when governments are inclined to cut social public spending. An ongoing dialogue between providers and local authorities on how the providers can support the roll-out of personal budget schemes represents an exemplary way to ensure high quality social care services.

[12] Office for Public Management, Briefing paper 5: Impact of Personal Budget on Providers, findings from the third round of three-year longitudinal study in Essex, September 2012.
[13] ACEVO Association of Chief Executive of Voluntary Organisations, An Introduction to personal budges. 2010.

V. Views and opinions of different stakeholders at EU level

The commentary made so far shows that people with disabilities who can be active in choosing their own services and making decisions about their care are able to enhance their quality of life, and that this process also improves services. At European level the debate on the application of personal budget programmes focuses on how national policies promote person-centred community-based services and independent living. Independent living, community support and personal assistance for disabled people are a right under the UN Convention on the Rights of People with Disabilities (UNCRPD). Article 19 states: that disabled people should be able to live where and with whom they wish; that they should enjoy a range of community support services including personal assistance; that they should enjoy community life and its opportunities on an equal basis with non-disabled people; and they should not be subject to isolation or segregation. Providing service users with their own funds is thus an important step towards independent living.

A number of European policies support the implementation of the UNCRPD. In the European Disability Strategy 2010–2020, the European Commission has committed to facilitating the full participation of people with disabilities in society by promoting the provision of quality community-based services, including access to personal assistance. Furthermore, in its Resolution on the situation of persons with disabilities in the European Union[14], the European Council has called on the member states to ensure that disabled people can enjoy their human rights by taking measures to facilitate independent living and inclusion of disabled people in the community, and by providing them with access to quality care and support services. It has also asked member states to support the transition process from institutional care to community-based services. The European Union thus endorses the independent living approach and national legislation has been passed in many countries. Thanks to progressive practice and self-advocacy, many disabled people now have choice and control.

However, despite this process a gap remains between the high legislative principles and their financing and implementation. The application of personal budgets as a new way to finance disability services remains an internal choice for single governments, since personal budgets are financed by national/local public funding schemes. The economic crisis has led to a situation where EU countries are witnessing cuts in services for people with disabilities, with

[14] Resolution of the Council of the European Union and the representatives of the Governments of the Member States, meeting within the Council of 17 March 2008 on the situation of persons with disabilities in the European Union, Official Journal C 075 , 26/03/2008 P. 0001 - 0004

"devastating impact on personal budgets and consequently on independent living and on the process of transition from institutional care to community-based services"[15].

The European Network on Independent Living (ENIL)[16] that represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination, cited a number of instances, where people with disabilities have had their personal assistant hours reduced and where local authorities have ceased offering support services, even in EU member States which had been leaders in promoting independent living. In other member States, people had to endure substantial periods on waiting lists for personal assistance services, cuts in the level of pensions and community based services. In the United Kingdom the Independent Living Fund, which supports people with severe disabilities to live independently is closed to new applicants and will be eliminated by 2015. In Sweden the government has reduced the hours of personal assistance being granted to people in need. In Flanders (Belgium), waiting lists for necessary support are effectively indefinite with over 5,500 people waiting for a personal assistance budget. In Ireland 21% of people registered with the National Physical and Sensory Database were waiting to be assessed for personal assistance and support services. ENIL supports the application of personal budgets as new paradigm to provide health and social care services to people with disabilities and improve the quality of their lives. At the same time, ENIL considers personal budget schemes a "courageous governmental choice" leading relevant changes within the welfare system and around the concept of services provision. Service providers play a key role in this transition phase by adopting an entrepreneurial approach and a new vision of care and support. Providers should be proactive in promoting the changes and offering to personal budget holders the alternatives they need for their care.

The European Disability Forum (EDF)[17] is now writing a position on personal budgets, but the arguments defending personal budgets from financial cuts are highlighted in the position on the impact of European governments' austerity plans on the right of people with disabilities.

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[15] ENIL Proposal for a Resolution of the European Parliament on the effect of cuts in public spending on persons with disabilities in the European Union: Background note, September 2011.

[16] The European Network on Independent Living (ENIL) is a cross-disability organisation, working across the European Union to promote independent living and the implementation of the UN Convention on the Rights of Persons with Disabilities. ENIL's mission is to advocate and lobby for independent living values, principles and practices, namely for barrier-free environment, de-institutionalisation, provision of personal assistance support and adequate technical aids, all of which make full citizenship of disabled people possible.

[17] The European Disability Forum is an independent NGO that represents the interests of 80 million Europeans with disabilities. EDF is the only European platform run by persons with disabilities and their families.

VI. Conclusions

The analysis conducted in this paper shows that personal budgets can positively contribute to reform the social care systems, providing that public authorities are in favour of considering some critical success factors, as experienced in some EU countries:

- Eligibility criteria to apply for a personal budget should be clear and not too broad;
- Administrative rules and regulations should be clear and workable for budget holders;
- Adequate support should be available so that budget holders can use and administer their budgets without the need for brokering organisations.

The introduction of personal budgets provides an opportunity for people with disabilities to achieve a higher level of choice and control over the support they may need and greater inclusion in society for the benefit of all. In the implementation of personal budget programmes it is important to keep an empowerment approach which aims to support people with disabilities to improve the quality of their life, and refuse a consumerist approach that risks pushing service users towards a prejudicial use of personal budgets to the detriment of quality of life.

Another challenge to the implementation of personal budgets is that some models appear to work well for some categories of services users and not for others, especially in relation to people with disabilities. People suffering mental health problems reported a significantly higher quality of life; adults with physical disabilities reported receiving high-quality care services; and people with learning disabilities were more likely to feel they had more control of their daily lives. Yet older people reported lower psychological wellbeing due to the difficulties they faced as a result of planning and managing their own support. It is therefore important to attempt to address these different needs, whilst preventing the fragmentation of service provision.

Service providers play a key role in supporting the application of personal budgets for health and social care services. At the same time they need support to negotiate personal budgets because often they operate in a context characterized by possible barriers, such as geographic distance, racial and ethnic prejudices, mental capacity issues and discriminatory attitudes. Information and support, clear policy guidance, legislation and advice on decision making capacity are all key issues for the equitable provision of personal budgets.

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