



The Center for Independent Living Submission to the Task Force on Personalised Budgets

October 20th

“Independent Living is not doing things by yourself... it is being in control of how things are done.”
(Disability activist, Judy Heumann)

What is Independent Living?

The Independent Living philosophy originated from the very first Center for Independent Living (CIL) established in Berkeley, California in 1972. That CIL was developed by a group of people with disabilities to support the development of a new perspective on disability – one that focused on the empowerment and civil rights of people with disabilities. It supported and encouraged them to leave residential care and live independently in the community.

Up to this point people with disabilities were passive and dependent, living solely in institutions or in the family home. They were part of a ‘medical model’ – which viewed a person with a disability as a patient, to be rehabilitated or cured, or at least helped adapt in order to fit in with society. Services for people with disabilities were designed by people with no personal experience of the issues, merely their perceptions of what was needed.

What is the Social Model of Disability?

The Independent Living (IL) philosophy however promotes a ‘**social model**’ of disability – with the premise that people with disabilities have a right to actively participate in, and contribute to, society as equals and without dependence on family, institutions or charity. The social model recognises that people with disabilities are prevented from achieving their full potential by the attitude of society, as well as environmental obstacles such as restrictions in their access to public transport, entertainment and public places, and in education and employment. The focus is not on rehabilitating the individual with a disability therefore, but on rehabilitating society and the environment, in order to make it accessible and create inclusion for the person with a disability as a participant, rather than as a patient. *It is recognised that the real experts when it comes to designing services are those with the closest possible experiences of the issues – people with disabilities themselves.*

What is the philosophy of Independent Living?

The philosophy of IL espouses living like everyone else – having control of one's own life, having opportunities to make decisions that affect one's life and being able to pursue activities of one's own choosing, regardless of disability.

It means “the right of all persons regardless of age, type or extent of disability to live in the community, as opposed to living in an institution, have the same range of choices as everyone else, participate in the social, economic and political life of their communities, have a family, live as responsible respected members of their communities with all the duties and privileges that this entails and unfold their potential.” (Adolf Ratzka, Disability Activist 2002)

This means challenging the person living with a disability to define their basic needs and empowering them to think differently, moving from a traditional passive dependent status to one that actively engages them in making decisions directly affecting their daily lives. It also means challenging community and state to provide the same range of choices to a person with a disability as to everyone else, in areas such as housing, transport, education and employment.

Independent Living therefore is not just concerned with the routine physical tasks of day-to-day life, but is more about a way of life and a state of mind. It is about self-actualisation; taking control of one's own life; exercising choices; taking responsibility while also allowing for the dignity of risk and the freedom to fail. It is also a social and political movement that is changing the way services are provided and the role people with disabilities play in society.

Independent Living in Ireland

The first Irish Centre for Independent Living (CIL), CIL Carmichael House, was established in 1992 by, and for, people with disabilities. Its main aim was to ensure that people with disabilities achieved independent living and full participation in society. A grassroots Organisation, it offered an advocacy and a campaigning representation role for people with disabilities. It strived to bring about a social model of service delivery, to ensure policy decisions would include input from those whose lives were actually affected rather than solely from the non-disabled professionals working in the disability industry. It also held an action-research role in the international world of Independent Living, monitoring developments, and pursuing action (or change) and research (or understanding) at the same time, thereby learning from experience. This took the form of a four-year programme with a European partner Organisation. The programme facilitated 28 adults with disability to train as leaders in Independent Living and to actually live the philosophy. The research part of the programme documented the success of this new development as well as introducing best practice in IL from EU and US.

Leaders Directing their Personal Services at the Core of Independent Living

It was recognised that in practical terms Personal Assistance was at the core of Independent Living, and the early days of CILs in Ireland were greatly concerned with creating a consumer-controlled Personal Assistance (PA) service. A PA is someone who provides a person with a disability (referred to as a ‘**Leader**’) with physical assistance to help them in all aspects of daily life from personal care, household tasks, assistance in college or the workplace, driving and interpretation. The PA works to their employer’s – the Leader’s – agenda. Their role is to assist, not to provide care for or tell the Leader what is best for them. PA services enable the Leader to make their own decisions and be in control of their own life, opening up opportunities in education, employment, socially etc.

Central to the effective delivery of personalised budgets: An Independent Assessment of Need (IAN)

The success or failure of any attempt to move to genuine Individualised Budgets/Direct Payments relies entirely on the full implementation of Independent Assessments of Need (IAN) under section 8 of the Disability Act (2005).

Section 8.2 of the Act states that “An assessment officer shall carry out assessments of applicants or arrange for their carrying out by other employees of the Executive or by other persons with appropriate experience.”

The UNCRPD defines a disability as an “interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”. Disability is not a medical issue and an assessment of need should not be led by the HSE as a body with responsibility for health care provision. Given that Section 8.2 of the Act states that “An assessment officer shall carry out assessments of applicants or arrange for their carrying out by other employees of the Executive or by other persons with appropriate experience”, the Center for Independent Living feels that in order to provide an accurate assessment of need, the assessment must be carried out an independent group.

Given that Section 8.5 of the Act states that “an assessment under this section shall be carried out without regard to the cost of, or the capacity to provide, any service identified in the assessment as being appropriate to meet the needs of the applicant concerned” the Center for Independent Living contends that IANs cannot be carried out by bodies charged with delivering services or managing current resources or budgets.

To meet these commitments under the Act, the AN must be carried out by an independent body, who can work in conjunction with a disabled person to fully identify both their needs and the supports and services required to achieve Independent Living – without having to worry about whether such supports, services or available budgets exist. The body can be resourced by the State to carry out the assessment, but must have the freedom to act separately from the delivery of services of resource allocation.

From the perspective of the Center for Independent Living, currently the only agency with the capacity to carry out genuine Independent Assessments of Need is SAOR Independent Living.

SAOR a DPO, employs disabled and non-disabled professionals in the effort to produce thorough, and solid, assessments and reports. This approach combines the lived experience and professional assessments and expertise working with the disabled person to produce an independent assessment of need.

Given commitments under 8.2 that the HSE can be carried out by or by other persons with appropriate experience CIL recommends that SAOR as a model be resourced as a truly independent approach to assessment of need in order to replicated as a model of best practice.

Without a genuine IAN, the framework of Individualised Budgets/Direct Payments is impossible. Without an IAN, the allocation or calculation of funds to be allocated to an individual’s budget/payment will be patchwork and ill-suited to the person’s actual needs. It will also lead to a lack of a cohesive approach across CHO areas, counties, or even HSE staff members.

There must be a comprehensive and steady methodology used across all areas to ensure that the full needs of each disabled person will be being identified, that consistent rules and frameworks will be

used to allocate funds. This approach in allocating resources through an independent assessment must influence policy and the allocation annual budgets to ensure that the resources currently being allocated under disability by the Exchequer is actually meeting the needs of people with disabilities. Ultimately this approach will ensure that people with disabilities will have choice and control in where and how resources are allocated leading to recognising the variety of supports that can be needed for people with disabilities to actively participate in society, in accessing education, employment and the full range of familial, community and social engagements that make up the experience of independent lives as directed by people with disabilities themselves.

How the Center for Independent Living developed this submission

One of the core principles of the work of CIL is that we are a grassroots organisation, directed by the lived experience of people with disabilities. Staff in CIL support leader forums across the country and the questionnaire was sent to them and discussions were had to ensure that the lived experience of people with disabilities could inform and directly shape this submission.

Responses to the Questionnaire:

1. In your opinion, what should personalised budgets be used for?

From the perspective of leaders consulted in the development of this submission, personalised budgets need to be under the control of people with disabilities. Therefore personalised budgets should be used to meet the needs of people with disabilities, how they chose in order to live their lives.

Personalised budgets are about giving people freedom to chose, what services they need and control over their lives. What a leader choses will depend on their specific circumstances, which will change over the course of their lives as their needs change (such as support in education leading to employment, which may require different supports). It could reflect different needs based on social choices available or flexibility needed due to changes in people's lives. Leaders are the experts in their own specific needs and what they require to meet those needs and personalised budgets should provide an opportunity for those needs to be met.

Personalised budgets should include:

- Assistance with getting up, using the toilet, bathing, dressing, preparing food, eating
- Domestic services: cleaning, washing, shopping and looking after children.
- Social activities: socialisation, visiting family and friends, leisure activities, holidays and travel.
- Employment and education: assistance getting to work, assistance in the workplace or at college.
- Support Workers
- Home supports
- Therapeutic services including physiotherapy, speech therapy, occupational therapy
- Aids and appliances
- Respite for the person with a disability
- Advocacy services

- Social supports and the vital role they play in reducing the isolation experienced by many people with disabilities.
- Training and day places – removing the limitation of the existing definition of ‘day places’ to community based education and occupational activities that will enhance an individual’s quality of life, employment prospects and life-long learning.

2. With reference to the supports and services available for this phase of implementing personalised budgets (Section 4), what are the top 3 things you think people would spend a personalised budget on (e.g. personal assistance services, home support, residential services, adult days services in line with New Directions, respite services, etc)?

As per our answer for question one, the ethos for development of personalised budgets should be based on the right of leaders to chose their own specific needs in order to lead an independent live. It is impossible to accurately predict what the top three things people will need or place a hierarchy on the level of supports leaders will need, which will change over their course of their lives.

Core to all leaders responses was that personalised budgets should include Personal Assistance Services and Home Assistant Packages to include other Independent Living Supports, including respite (if needed). Secondly, personalised budgets should include other aspects of life which allow people to participate in society- such as transport and education supports.

Coupled with those personalised budgets should be used to build the awareness of the philosophy of independent living. People who have lived in institutions or in family settings without freedom to chose have often built a dependency on others and personalised budgets should be used where needed to ensure Leaders are confident to build their confidence in independent living and choices they can make.

3. From your perspective what are the key advantages in having a personal budget?

The key perspective is that personalised budgets by their nature give choice and control and in doing so allows leaders to control their lives and have their supports be flexible and meeting their needs. Leaders will be able to “shop around” and find the best value. They will be able to seek new supports if the supports they are paying for are not to the standard they want. Leaders can define what the roles of their Pas will be. Personalised budgets are empowering and allow for agency to change and control for leaders to get what they need in living their lives. Having control over your budget shifts services from being something you access towards something you control and have a right to manage.

4. From your perspective, what would be the biggest challenges in administering personal budgets?

Given that this is a new system, some leaders have concerned on specific management issues, namely fears around having to set up a company or as a sole trader, complying with employer legislation, keeping adequate records to account for money spent etc. The pressure of managing the budget to ensure sufficient resources to maintain supports was a concern, especially if people have come from an institutional setting (or indeed familial setting) where leaders previously have not had the freedom to manage their own money.

The were concerns raised about the nature and condition of the person with the disability and issues relating to capacity and whether they could be exploited.

Leaders noted that the development of an administrative system that recognises the dignity and freedom of people with disabilities could be the biggest barrier or challenge. A system that has been build on creating dependency will be very challenged by the development of a system that is based on independence, choice and freedom.

5. What supports do you think would need to be put in place to help people to use a personalised budget?

People with disabilities need to be informed that they will have the right to personalised budgets, what this will mean and how they can use them and that if there are supports needed in accessing this, they will be provided. This will remove the fear that people with disabilities might have that they cannot access personalised budgets or that they lack the capacity to manage them and therefore not seek this option at all.

Supports must be person centred and based on skills, knowledge and experience – no one size fits all in terms of supports. There is no “one size fits all” approach here. There is a need for flexibility around how supports are provided to ensure that they are as accessible as possible. Training from the outset around budget management and administration of funds is vital including training around what the funds may and may not be used for. Mentoring from other leaders with lived experience of using personalised budgets will be vital and those people with disabilities who have experience and skills should be targeted to be employed to act as mentors within the delivery of personalised budgets.

As stated at the outset of our submission, crucial to the success of a personalised budget will be an independent assessment of need, which is independent of Statutory agencies delivery services. The model as provided by Saor needs to be resourced, expanded and endorsed as a way to provide this independent assessment of need as a way of accessing a personalised budget.

6. What changes do you think having a personalised budget would make to the life of a person with a disability?

There are multiple effects personalised budgets could have. Having freedom to chose your services to direct your life will enhance self-belief in people with disabilities to chose and redefine what services and supports they need based on their choices. It will shift the perspective from being dependent on services and passively accepting to being in control, accessing a budget as a right and exercising a right to choose what you want.

7. What is one important change you would make to the way you use services and supports are provided if you had a personalised budget?

Like questions one and two, these answers are impossible to answer from a collective response as they will be dependent on each individuals assessment of their services and what their needs are at that moment in time. However, a considerable number of leaders expressed that a personalised budget will allow greater PA hours instead of home help. Also, if you could employ your PA there is greater consistency rather than change based on PAs employed via the CE scheme.

8. People using a personalised budget will have to provide some information on how it is being spent by them. What type of information would you think could be shared?

Given that the funding is provided by the exchequer, there is an expectation that some information such as breakdown on wages etc can be provided. However, there is precedent in that statutory funds (eg childcare) is provided on the proviso that it offers a specific support yet there is no administrative requirement for parents to prove the money is directly spent solely on childcare.

9. Do you have any other ideas on personalised budgets that you would like to include?

The information on personalised budgets, including resourcing people with disabilities who have managed their own budgets to act as advocates for the service, needs to be accessible and made available to all people with disabilities in order that they can make informed decisions to access a personalised budget. Where people need support to make decisions in their best interest, these also should be provided as per the legislation under assisted decision making. Personalised budgets should be available to all people with disabilities and central to this is the need for a truly independent assessment of need.

Personalised budgets should be controlled, directed and owned by people with disabilities. At times, people with disabilities can be in conflict with family members who may not be able to recognise that independent living is possible for people with disabilities and assume that they as family will need to maintain control.

However, central to the right to choose is the right to choose not to have a personalised budget. In order for people to make an informed choice, accessible information needs to be made available at all times on what personalised budgets mean and how they operate and what supports are in place. The option to re-examine choices to access personalised budgets should remain an option at all stages of life for people with disabilities.