

National survey on the prevalence of personal budgets

Executive Summary

The National Disability Authority has been asked to gather baseline data on the prevalence of personalised budgets in Ireland. The anonymised data in this national survey will be used to inform the work of the Task Force on Personalised Budgets. The survey was sent to 139 disability service organisations including the nine HSE Community Healthcare Organisations in March 2017. Thirty-one organisations responded giving a response rate of 22%. Of these, 12 organisations (37%) had somebody who received a personal budget representing 290 individuals. The analysis included 11 organisations and 283 individuals.¹ Some of the key findings are bulleted below.

- 57% of people had an intellectual disability as their primary disability
- 60% were reported to have a complex need
- 63% were male
- 59% were between the ages of 19 and 40
- Most people (73%) received less than €51,000 at a total cost of just over three million euro
- 27% received €51,000 or more amounting to over eight million euro
- The proportion of the budget used for administration varied between 5% and 10.6%
- The most common method by which the budget was distributed was directly to the service provider (79%)
- The most common method to determine the amount of budget allocated was an individualised support plan (54%)
- The most common methods for monitoring personal budgets were verification from service providers and an annual review of individual payments
- The personal budget was most often used for personal care, followed by social activities and activities of daily living
- The most common reason that a personal budget was given was that there was no alternative service or place available (48%)

¹ One organisation did not complete the questionnaire so is excluded from the main analysis

More in-depth analysis such as average cost by disability type was not possible as the information was not collected at the individual level. Collection of data at this level would require a much more detailed survey, conducted over a longer time frame with permission sought from individuals in receipt of a personal budget.

Respondents were asked about the **challenges in administering a personalised budget**. Twenty-one organisations responded to this question. A number of challenges were noted by services providers. These included:

- Administration relating to
 - budget and monitoring expenditure
 - oversight and governance
 - setting up the funding arrangement
- The lack of a legislative/policy framework
- Support for families and individuals
- Assessment of need
- Possible negative implications of a personal budget

Respondents were asked about the **advantages of a personalised budget**. Twenty-three organisations responded. The most frequently mentioned advantages were choice (n=10), person-centred / individualised approach (n=10), flexibility (n=9), control (n=8) and empowerment (n=8).

1. Introduction

The establishment of a Task Force on Personalised Budgets is a key element in the Programme for Government's commitment to give people with disabilities greater control, independence and choice in terms of obtaining HSE-funded personal social services and supports.² The National Disability Authority has been asked to gather baseline data on the prevalence of personalised budgets in Ireland. This document reports on the findings of that survey and should inform the work of the Task Force.

2. Methods

The National Disability Authority designed and tested a questionnaire on personal budgets. We included a range of definitions to try to capture the current situation and the variety of ways personal budgets/individualised budget arrangements are provided. The definitions provided can be found in Appendix 1. In summary, it includes:

- Payment of a personalised budget to an individual
- Unbundled funding by a service provider for an individual
- Individualised funding arrangement for a person specified in a Service Level Agreement, whereby, an individual is provided with a service by the provider

Some of these funding types could be considered as individualised funding arrangements rather than personal budgets but for convenience we only use the term 'personal budget' or 'personalised budget' throughout this report.

The survey was sent to 130 non-statutory disability service providers based on a list provided by the HSE of all disability services they fund. It was also sent to the nine statutory Community Healthcare Organisations (CHO) of the HSE. Dissemination was via e-mail in March 2017 through the relevant person in the HSE and directly to the disability service providers. Multiple reminders were sent and certain organisations, thought or known to have people with personal budget arrangements, were e-mailed or contacted directly by phone.

We requested people to respond, whether or not they had people with personal budgets, as questions on challenges and advantages of a personal budget were included that could be answered by all. Data have been anonymised with no organisation identifiable in this report. The response rate was poor with an overall response rate of

² This is shorthand to describe the broad category of non-clinical services and supports which the HSE funds from its budget for specialist disability services.

22%, with 20% of non-statutory organisations and 56% of statutory organisations responding (Table 1).

Table 1: Survey response rate

	Number sent	Number returned
Community Healthcare Organisations (Statutory)	9	5 (56%)
Disability service providers (Non-statutory)	130	26* (20%)
Total	139	31 (22%)

*30 responses were received from non-statutory organisations but two organisations sent multiple responses from different geographical regions so there are analysed here as one organisation.

Table 2 shows the number of organisations reporting at least one person it serves having a personal budget. Just 40% of the statutory organisations and 38% of the non-statutory organisations who responded reported having at least one person with a personal budget.

Table 2: Proportion of organisations reporting at least one personal budget

	Number of organisations with people with a personal budget	Number of organisations without people with a personal budget	Total
Community Healthcare Organisations (Statutory)	2 (40%)	3 (60%)	5
Disability service providers (Non-statutory)	10 (38%)	16 (62%)	26
Total	12 (37%)	19 (63%)	30

Table 3 shows the number of people by organisation with a personal budget. Overall there were 290 people with disabilities who were reported to have a personal budget across the 12 organisation. Most individuals (97%) were supported by non-statutory organisations. The number of people per organisation ranged from one to 77. Five

organisations made up over three quarters (78%) of all people with and individualised budgeting arrangement.

Table 3: Number of people reported to have a personal budgeting arrangement in place

Organisation	Number of with people with a personal budget
Organisation 1 (Non-statutory)	77 (26.6%)
Organisation 2 (Non-statutory)	54 (18.6%)
Organisation 3 (Non-statutory)	37 (12.8%)
Organisation 4 (Non-statutory)	30 (10.3%)
Organisation 5 (Non-statutory)	28 (9.7%)
Organisation 6 (Non-statutory)	19 (6.6%)
Organisation 7 (Non-statutory)	13 (4.5%)
Organisation 8 (Non-statutory)	10 (3.4%)
Organisation 9 (Non-statutory)	8 (2.8%)
Organisation 10 (Statutory)	7 (2.4%)
Organisation 11 (Non-statutory)	6 (2.1%)
Organisation 12 (Statutory)	1 (0.3%)
Total	290

One CHO area (with seven people with a personal budget) did not complete the majority of the questionnaire and is excluded from the remainder of this analysis. Therefore, the analysis below includes 11 organisations with 283 people supported with a personal budget.

3. Main findings

The majority of people with a personal budget arrangement had an intellectual disability as their primary disability (57%), followed by those with a physical disability (27%) (Table 4). Overall, 170 individuals (60%) were reported as having complex needs. Almost all people with autism, a physical disability or a sensory disability had a complex need. Of those with an intellectual disability, only 32% were reported to have a complex need. The nature of the complex needs were not well described by respondents but did include:

- Behaviours that challenge
- Mental health difficulties
- Physical and medical problems

- Dementia
- Sensory issues

Table 4: Number of people by primary disability type and complex needs status

	Autism	Intellectual disability	Physical disability	Sensory disability	Total
Number of people with a personal budget	40 (14%)	166 (57%)	77 (27%)	7 (2%)	290*
Number of people with a complex need	39	55	76	7	177**
% of people in each category with a complex need	98%	32%	99%	100%	60% (170/283)

*One organisation reported more than one primary disability (n=7).

** Multiple complexities were selected by one organisation (n=7) so the number with a complex need is 170.

Of the 283 people with a personal budget 63% (n=179) were male and 37% female (n=104). Most people were in the 19-30 age group (33%) followed by the 30-40 age group (26%) (Table 5). Only 1% were aged over 65 years of age.

Table 5: Distribution of age

Age group	Total (%)
0-18	18 (8%)
19-30	79 (33%)
30-40	61 (26%)
40-50	47 (20%)
50-65	30 (13%)
65+	3 (1%)
Total	238*

*Note not all respondents included age breakdown

Respondents were asked to indicate the funding allocated according to a series of bands. The bands up to €50,000 were taken from the 2016 school leaver allocation scale. For anyone who received greater than €50,000 the organisation was asked to indicate how much they received and these were grouped into new categories during the analysis. In order to estimate the overall cost of personal budgets the midpoint of each allocation band was taken and multiplied by the number of people in that band.

As can be seen in Table 6 information was provided for 249 people at a total estimated cost of €11,477,000. An additional 24 people in one organisation received an allocation of >€50,000 each but no breakdown was provided. Most people (73%, n=181) received less than €51,000 at a total cost of just over three million euro. Although less people received €51,000 or more (27%, n=68), this amounted to over eight million euro.

Table 6: Annual allocation and total estimated cost

Annual allocation band	Number (%) of people	Mid-point of allocation band	Estimated cost per band	Summary
Up to €7K	60 (14.1%)	€3500	€210,000	Receiving less than €51,000: 181 (73%) people Value €3,102,500
€8K -€13K	9 (3.6%)	€10500	€94,500	
€14K-€18K	31 (12.4%)	€16000	€496,000	
€19K-€26K	49 (19.7%)	€22500	€1,102,500	
€27K-€37K	19 (7.6%)	€32000	€608,000	
€38K-€45K	5 (2.0%)	€41500	€207,500	
€46K-€50K	8 (3.2%)	€48000	€384,000	
€51K-€70K	16 (6.4%)	€60500	€968,000	Receiving €51,000 or more: 68 (27%) people Value €8,374,500
€71K-€100K	18 (7.2%)	€85500	€1,539,000	
€101K-€150K	12 (4.8%)	€125500	€1,506,000	
€151K-€200K	8 (3.2%)	€175500	€1,404,000	
€201K-€300K	11 (4.4%)	€150500	€1,655,500	
€301K-€500K	2 (0.8%)	€400500	€801,000	
€501K+	1 (0.4%)	€501000	€50,1000	
Total	249		€11,477,000	

Of the six organisations who provided information about how the budget was allocated two said all the money went directly to the person with the disability and four said that it was split so administrative costs could be taken out. Of those who said the budget was split three provided information on the split. These were, in a ratio of service provider to service user:

- 95%:5% (for brokerage model) or 92%:8% (for traditional service provider model – both models were operating within the one organisation)
- 89.4%:10.6%
- 92.5%:7.5%

The most common method by which the budget was distributed was directly to the service provider (79% of individuals, eight service providers) (Table 7). No individual or their support worker received the budget directly. Ten percent of budgets were distributed directly to a family member. The use of a legal entity or broker was limited to one organisation.

Table 7: Method of distribution of the personal budget

	Total	Number of organisations
To the individual concerned	0	0
To specific legal entity representing the person	20 (7%)	1
To family member on person's behalf	29 (10%)	2
To broker who oversees personal budgets	10 (4%)	1
To disability service provider	224 (79%)	8
To support worker/carer/PA	0	0
Total	283	12*

*One organisation used both legal entity and broker

Nine organisations received their allocations monthly, two quarterly and two annually. Two of the organisations received their allocation both monthly and quarterly (varying by person or region). Of eight that replied to the question on whether they received their allocation on the same day, four said they did, three did not, and in one organisation it varied by area with one area receiving it on the same day and the other not.

The most common method to determine the amount of budget allocated was an individualised support plan (54%) (Table 8). This method was used by 10 of 12 organisations. However, for this method and for the agreed person centred plan and the standard assessment of need no information was given on the process used to monetise these assessments and plans. Multiple methods were used by some organisations. Of the 32 individuals for whom “other” was given as a reason, 30 said that the money was allocated by the HSE but did not specify the method used. One organisation stated that

the funding was allocated based on a reduction of centre-based respite allocation for the individual. The other was through conversations with person and family using range of planning tools and circle of support meetings. The two organisations that used a resource allocation tool used the HSE profiling tool for school leavers.

Table 8: Methods used to determine amount of budget allocated

	Total	Number of organisations
Standard assessment of need	56 (14%)	3
Resource allocation tool	4 (1%)	2
Agreed person centred plan	89 (23%)	4
Individualised support plan	210 (54%)	10
Other (please state)	32 (8%)	2

In most organisations a review took place annually. In two organisations they took place every three to five years and in another one it took place on an as needed basis. In one geographical area of a particular organisation reviews took place quarterly and in another it was reported that the frequency of reviews varies. One organisation indicated that for five of its clients they were never reviewed.

Some organisations used more than one method for monitoring personal budgets. The most common methods were verification from service providers and an annual review of individual payments (Table 9). Other methods mentioned included claim forms, review meetings with CHOs, and HIQA audits.

Table 9: Methods used to monitor the personal budget

	Number of organisations
Verification from service providers	6
Annual review of individual payments	5
Other (please state)	4
Contractual arrangements with those providing individualised supports or services	3
Outcomes measurement	3
External /internal annual /random audits	3
Receipts	3
Individual's bank statements	2
Report from Broker	2
Confirmation that contractual arrangements are fulfilled	1

We looked at the method of budget distribution by the method used to monitor the budget. One organisation who used either a legal entity or a broker to distribute the budget used multiple methods to monitor the budget. Only two organisations had family members who receive the personal budget on the person with a disability's behalf. Both annual reviews of individual payments and contractual arrangements were used to monitor these payments. Where disability service providers received the funding they used a number of methods to monitor the funding with internal verification the most commonly used method.

Table 10 provides a breakdown of the purpose for which the personal budget was used. Insufficient information was given at the individual level so this variable is analysed by organisation. The personal budget was most often used for personal care, followed by social activities and activities of daily living. Other activities included support to create and maintain valued roles and to support self-directed living.

Table 10: Purpose for which the personal budget was used

Activity/service/equipment	Number of organisations
Personal care (dressing, meal preparation and support, washing, etc.)	9
Social activities (for example, paid support for engagement in community activities)	7
Activities of daily living (for example, shopping assistance, PA, home help etc.)	7
Leisure activities	6
Transport	6
Employment support	6
Education/Classes support for participation	5
Exercise/Gym/Sport	5
Housing/ accommodation/home improvements	5
Special medical needs (such as, peg feeding, epilepsy support etc.)	5
Equipment/assistive technology	4
Medical/therapy supports	3
Other (please state)	3
Not known	1

Table 11 examines why a personal budget was allocated. The most common reason was that there was no alternative service or place available (48%). The next most common reason was that the service provider initiated the move to a personal budget (27%).

Table 11: Reasons for allocation of a personal budget

	Number of people	Number of organisations
Individual offered personal budget after consideration of the person's level of needs and no alternative service /place available	125 (48%)	5
Service initiated move to individual budget	71 (27%)	4
Specific request from a family member to have a personal budget for his/her son, daughter, brother, sister with a disability	38 (15%)	6
Individual/family requested to move from current service	26 (10%)	2
Specific request from the person with a disability to have a personal budget	2 (1%)	2
Other (HSE request)	1 (0%)	1
Total	262*	

*One organisation did not answer this question

4. Challenges

Organisations were asked what were their biggest challenges in administering personal budgets. Twenty-one organisations (three statutory and 18 non-statutory) responded to this question. Administrative challenges were the most frequently mentioned with all but two organisations mentioning these. The three statutory organisations almost exclusively mentioned administrative challenges. The points below offer a summary of the opinions and issues raised by the responding organisations and reflect their views based on the current landscape and current operating procedures.

4.1 Administrative issues

4.1.1 Opinions about administration relating to budget and monitoring expenditure

- Need to determine eligibility for the personal budget scheme and have clarity around what personal budget funds can be used for
- There will be additional costs associated with set up
- There will be challenges in monitoring the finances, for example, what accounting standards will be used by families
- There will be increased administrative and IT support to track individual expenditure

- The traditional 'economies of scale' associated with group budgets no longer apply so additional resources are required in addition to the unbundling of existing budgets
- There are difficulties in unbundling from block grants and therefore a new system of budgeting will be required
- There will be a need to determine costs associated with brokerage / administration
- There should be financial sustainability and service providers and CHOs believe this may require a cap on resource allocation
- The perception is that value for money must be demonstrated
- There was a concern expressed that there may be challenges in receiving payments on time
- There will be difficulties in administering payments when people with disabilities are receiving services from a range of service providers
- There will be a need for standard operating procedures for implementation

4.1.2 Opinions about administrative issues relating to oversight and governance

- There is a view that additional governance and oversight arrangements will be needed to ensure ongoing monitoring of risks involved and to ensure the budget is utilised in the most efficient way while meeting the needs of individuals
- There is a belief that there will be increased work at corporate and leadership level
- There will need to be a balance between appropriate governance and families/individual's choice and privacy
- There may be issues around governance in HIQA designated centres when individuals receive personal budgets

4.1.3 Opinions about administrative issues relating to setting up the funding arrangement within current structures

- Currently requires the development of service level agreements, or designing contracts for individual arrangements
- Currently requires regular service reviews, development and reporting on key performance indicators, and financial returns
- Currently requires the establishment of a legal entity to administer funding and the wind down of that legal entity should individual die

- Currently requires setting up individuals as sole traders, registering them with revenue as an employer, and ensuring insurance and relevant policies and procedures are in place

4.2 Perceptions of the current Legislative /policy framework

- The lack of a legislative / policy framework is considered an impediment to advancing a wider introduction of personal budgets
- Service providers believe there will be a need for supports to help them adapt to the introduction of personal budgets

4.3 Opinions about the need for supports for family and individual

Those who responded to the survey believe that families and individuals will require a number of supports outlined below which would have a resource implication:

- Training and support for the family and/or the individual in their role as an employer and in relation to issues such as tax liabilities
- Support with recruitment vetting, seeking references, medicals and payroll management (these supports are costly and are not always recovered through funding mechanisms)
- Clarity on employment issues, for example, the obligations of the service provider versus the individual / family in relation to staff, particularly for direct hires such as payment of maternity leave, insurance issues, governance, supervision, and health and safety of staff
- Support with staff training and ensuring training is up to date and clarify if direct hires will have to undertake mandatory training
- Support with getting the best match of staff
- Support in retaining staff – this will include looking at issues that are unattractive for staff such as split hours, lone working and lack of peer support
- Support to ensure safeguarding when using direct hire staff
- Clarity on whether a family members can be employed as a paid carers and what might be the advantages and disadvantages of this approach
- Developing and supporting Circles of Support, or similar, to support an individual to manage his/her own service
- Developing independent support infrastructure for families to manage personal budgets, for example, brokerage
- Clarifying, where a problem arises between the family and the person contracted to provide a service, who is responsible for dealing with this
- Clarifying whether families/individuals will have access to the ombudsman if they have a complaint

- Building capacity in families and individuals who are interested in this model

4.4 Perceptions of Assessment of need process

- There is a need to source an appropriate needs assessment tool and costing framework for identifying the resources to support the individual
- Those who responded to the survey believe there may be a difficulty in responding to wants versus needs and therefore some management of expectations may be required
- There is often an assumption that standard needs assessment tools can predict fluctuations in the person's needs which may not always be the case and therefore personal budgets may lack the flexibility to respond to changing need

4.5 Opinions of possible negative implications

Those who responded to the survey expressed their concerns raised about things they believed could go wrong or the potential negative implications of a personal budgeting system:

- If not administered and monitored adequately a personal budget scheme could narrow a person's life and experience – it could lack a person-centred approach
- As someone's needs change (increase) if the system lacks flexibility then resources may have to be taken from others, therefore reducing their choice and services
- There is a perceived risk that service providers may cherry pick as to what clients they will take
- Some people believed that maintaining boundaries between staff of a service provider and families could be a major challenge under a personal budget system
- There is a concern that individuals could struggle to purchase the same level of support they need and can currently access in a group setting
- There was a concern expressed by some respondents that families/individuals may overspend and run out of money for service
- There was a concern that there may be an adverse impact on those who choose not to avail of a personal budget if the implementation of a personalised budgets system is not managed appropriately
- Service providers (particularly smaller ones) need to be able to predict their funding and are concerned that this may not be possible if personal budgets are used
- Service providers are concerned that they might experience difficulty in keeping staff if core funding moves to services users' own budgets
- The limited availability of some specialist services and some good quality services may limit choice

A number of other comments were made. There was a recognition by one service provider that the introduction of personal budgets would represent a huge cultural change. A key point coming through from organisations was the need to be flexible to accommodate changing / enhanced needs. However, there seemed to be a belief among some service providers that individuals would retain access to services already provided, for example, clinical and respite, and would use their personal budget for shortfalls in the system. There was also reference to the fact that funding is currently redistributed internally depending on need, for example, from one individual to another, and there was a sense that this should continue in a personal budget system. Only one organisation mentioned that the services and personal budget should align with the achievement of positive outcomes. Another organisation mentioned how we need to think through how advocacy organisations will continue to be a key support for individuals.

5. Advantages

Organisations were asked about the key advantages in having personal budgets. Twenty-three organisations (three statutory and 20 non-statutory) responded to this question. The advantages of choice (n=10), person-centred / individualised approach (n=10), flexibility (n=9), control (n=8) and empowerment (n=8) were all frequently mentioned. These issues raised and the views expressed by the various organisations are set out in more detail below.

5.1 Choice

- A perception of increased choice for people with disabilities in their day to day living by deciding where and how they receive a service and individual supports
- Intentionally pursuing a good life based on real needs
- No longer a service provider driven model
- A perception that it may have particular benefit for those in isolated and rural areas
- A belief that it will allow access to specialists outside of their geographic area and may allow more timely access to services as individuals will be able to go outside the public system

5.2 Person-centred / individualised approach

- A belief that the individual can now structure their supports around their life and not their life around the supports
- A personal budget enhances opportunities
- They can choose and hire the staff they feel are most suited to them

- They can avoid some of the negative impacts of peer on peer interactions that can take place in group settings
- A personal budget system may be particularly beneficial to individuals who don't readily fit within a traditional service model
- It allows a person to develop and grow their identity and develop positive and normative expectations of and for themselves

5.3 Flexibility

- Belief that a personalised budget will offer flexibility in when, where and from who the individual can receive a service
- Services can be accessed when it suits the individual as opposed to when the service can be offered
- Flexibility to adapt and change things as needed
- Flexibility to work at the person's pace
- Allows for more creative solutions to care packages

5.4 Control

- Perception that a personalised budget will foster an individual being in control of what they need and when they need it
- Gives insight into their package and may aid in managing expectations
- Control allows prioritising what the person wants to spend their money on and potentially make savings
- The focus can be on achieving a properly funded service package for the person – education/social supports and housing/training/social protection entitlements
- It would challenge the existing model of provision and provide another option for families / individuals
- Encourages the development of alternative modalities of service provision in a more holistic way

5.5 Empowerment

- The individual is empowered to choose their own supports and self-direct the services they receive
- Enhances skills of the individual in management, being an employer, governance, accountability, policies and procedures
- Increases understanding of funding attributed to their service and how they can get best value for money
- Enhances access to mainstream services

- There is a belief among service providers that access to a personalised budget can foster growth in the person's confidence, self-esteem, participation in the community, finding their voice, speaking up and self-directing their lives
- May renew families so that they can focus on what is important in the individual's life
- Can solve challenges together with service provider and share responsibility and risks
- Is part of a rights based approach that empowers the person to be engaged
- Personal budgets would be a gateway to full citizenship for deaf people allowing access to Sign Language interpreters
- Perceptions of greater opportunity for the individual to access their local community, become integrated, and to be an active citizen

5.6 Opinions of service providers/CHOs regarding other advantages

- A personalised budgets system will allow the real cost of service provision for an individual to be determined
- Cost-effective and better value for money
- Increased facility for budgetary control
- More transparency in how funding is spent and what families / individuals pay for
- The service will be more equitable
- There is a belief that there will be greater accountability for service providers in the service they deliver
- There is a perception that services will become comparable
- Perception that it will support the development of inter-agency alliance, collaboration and partnership

6. Conclusion

The low response rate does limit the generalisability of the findings, and where views were expressed they are the personal opinions of the organisation/service provider in question. However, this survey does provide some useful information on the use of personal budgets in Ireland, not least, the lack of any standardized and centralized information on personal budget arrangements. This information may be helpful to the Task Force in drawing up its criteria around what personalised budgets may be spent on and may help to predict the future demand for personalised budgets. It will also allow the preparation of contingency plans for any variation between what spending will be permitted with a personalised budget versus what budgets are currently spent on. It

also allows the Task Force to consider some of the challenges that service providers are and will be presented with under a personalised budgeting arrangement.

More in-depth analysis such as average cost by disability type was not possible as the information was not collected at the individual level. Collection of data at this level would require a much more detailed survey, conducted over a longer time frame with permission sought from individuals in receipt of personal budgets. It would be more useful perhaps to explore some critical issues in further detail with relevant stakeholders – either service providers, brokers or individuals with disabilities. The findings of this survey may offer a direction for such follow-up conversations if they are deemed helpful to the work of the Task Force.

Appendix I: Working definitions used for this survey

For the purpose of this **survey only** a personal budget is understood as:

- a method of delivering services by providing funds directly to individuals or their families, so that they can purchase individualised services which support their own vision of how they want to live and how they want to participate in their community and/or
- a way of paying for disability support services. It enables the person with a disability to directly manage the hours one is allocated for home and community support services. This could range from simply choosing support workers and planning how best to use the hours of support, to employing support workers and managing all aspects of the service delivery and/or
- as a payment for self-directed support, a term that describes the ways in which individuals and families can have informed choice about how their support is provided to them and/or
- as a payment made directly to someone in need of care and support by the HSE/ service provider to allow the person greater choice and flexibility about how his/her support/care is delivered and/or
- a personal budget that allows individuals with disabilities to buy and organise one's own care/support instead of receiving care in kind. Personal budgets are available for health and social care

The types of individualised/personalised funding to be captured in this survey include:

- Payment of a personalised budget to an individual
- Unbundled funding by a service provider for an individual
- Individualised funding arrangement for a person specified in a Service Level Agreement, whereby, an individual is provided with a service by the provider

Appendix 2: Questionnaire

Two separate questionnaires were prepared for statutory and non-statutory organisations. As they were almost identical they have been amalgamated into one questionnaire in this document.

1. Name of organisation or CHO area		
2. Total number of people with disabilities who are currently in receipt of a personal budget ³ 1) For statutory providers funded directly by the HSE (do not include non- statutory service providers). 2) For non-statutory providers funded directly by your organisation nationally		
3. Types of disability of those in receipt of personal budgets		Insert number against primary disability type
		Autism
		Intellectual disability
		Physical
		Sensory
		Not known
4. Complex Needs based on the numbers in section 3 above how many would be deemed to have complex needs ⁴		
State total number for each category	Disability	(specify nature of complex needs)

³ If none insert 0 in the box and go to sections 15,16 and 17. If the answer is one or more please complete the rest of the survey.

⁴ A definition of multiple and complex needs implies both:

- breadth of need – multiple needs that are interrelated or interconnected.
- depth of need – profound, severe, serious or intense needs

and that requires an individualised response.

	Autism	
	Intellectual disability	
	Physical	
	Sensory	
	Not known	
5. Gender	Female	Male
(insert total number against gender)		
6. Age profile	(insert total number against relevant age bracket)	
	0-18	
	19-30	
	30-40	
	40-50	
	50-65	
	65 +	
7. Amount allocated annually	(state total number against relevant banding for the personal budget ⁵)	
	Up to €7K	
	€8K -€13K	
	€14K-€18K	
	€19K-€26K	
	€27K-€37K	
	€38K-€45K	
	€46K-€50K	
	€51K +	
	(please state the actual individual amounts in excess of €51K and the number of recipients)	
8. Allocation and method of payment	Number of people	

⁵ Banding structure is aligned with current school leaver banding for adult day services (New Directions)

All budget goes to the individual/family			
Distribution of budget between individual and a service provider relating to administration, brokerage, overheads etc.			
If distributed please state the average % split giving the individuals % first (e.g. 70:30)			
State number against relevant method . People can be included in more than one category			
To the individual concerned			
To specific legal entity representing the person (for example, microboard)			
To family member on person's behalf			
To broker who oversees personal budgets			
To disability service provider			
To support worker/carer/PA			
Other (please state)			
Not known			
9. Frequency of payment			
Frequency	State number against frequency level	All payments made on the same day-please ✓	
		Yes	No
Weekly			
Monthly			
Annually			
Other (please state)			
10. Resource allocation - methods used to determine amount of budget allocated		State number against relevant method. People can be included in more than one category	
Standard assessment of need			
Resource allocation tool (specify)			
Agreed person centred plan			
Individualised support plan			
Other (please state)			
11. How often is needs assessment reviewed. Please		Annually	
		Once every 2 years	

√ relevant review period.	Once every 3 -5 years	
	Other (state)	
	Never	
12. Methods used for monitoring of personal budgets. State number against relevant method. More than one method can be recorded for an individual		
Annual review of individual payments		
Individual's bank statements		
Report from Broker		
Verification from service providers		
Contractual arrangements with those providing individualised supports or services		
Confirmation that contractual arrangements are fulfilled		
Outcomes measurement		
Random audits		
Receipts		
Other (please state)		
13. Purpose for which personal budgets are used. State number against relevant purpose. If not known use a √ in this box <input type="checkbox"/>		
Activities of daily living (for example shopping assistance, PA ,home help etc)		
Education/Classes support for participation		
Employment support		
Equipment/assistive technology		
Exercise/Gym/Sport		
Housing/ accommodation/home improvements		
Leisure activities		
Medical/therapy supports		
Personal care (dressing, meal preparation and support, washing, etc.)		
Social activities (for example, paid support for engagement in community activities)		
Special medical needs(such as, peg feeding; epilepsy support,		

etc.)	
Transport	
Other (please state)	
I 4. Rationale for personal budgets. From your perspective please state the reasons why a personal budget was given. You can pick more than one reason and indicate the number of people against the relevant reason(s)	
Reasons	Number
Individual offered personal budget after consideration of the person's level of needs and no alternative service /place available	
Individual/family requested to move from current service	
Service initiated move to individual budget	
Specific request from the person with a disability to have a personal budget	
Specific request from a family member to have a personal budget for his/her son, daughter, brother, sister with a disability	
Other (specify)	
Not known	
I 5. Challenges in administering personal budgets. From your perspective what are the biggest challenges in administering personal budgets? Challenges: Primarily the challenges will relate to families who do not use a brokerage system	
I 6. What are the advantages of having a personal budget? From your perspective what are the key advantages in having a personal budgets Advantages:	

17. Individuals who have ceased using personal budgets.

Please state the number of individuals who previously had a personal budget but have ceased using it and have switched back/relinquished the personal budget. Please state the total number of individuals _

If not known use a √ in this box ☐

Please state the reasons for switching back:

If not known use a √ in this box ☐

Reasons:

Contact details (should we need to get clarification from you)

Name:

Phone:

Email: