

Towards Personalised Budgets for People with a Disability in Ireland

Report of the Task Force on
Personalised Budgets

June 2018

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MINISTERS FOREWORD

A central goal of the Government's reform programme for disability services is to support people with disabilities to live independent lives in the community and to make their own choices and decisions. This is embodied in Transforming Lives, the programme to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland. It was also the driving force behind the Programme for a Partnership Government's commitment to the establishment of a Task Force on Personalised Budgets and I am pleased to see that the principles of choice and control are fully reflected in this Task Force report.

One of my principal objectives in setting up the Task Force was to see that service users, people with disabilities, and their families were fully represented in the process and without doubt their active participation on the Task Force greatly enhanced and informed its work. The Task Force also arranged a public consultation to ensure that all of those with an interest in personalised budgets had an opportunity to have their voices heard.

The approach adopted by the Task Force in examining the evidence base, considering international experience and most importantly, in engaging and consulting with service users, civil society and stakeholders has ensured that this Report provides an informed and robust roadmap for moving forward with personalised budgets.

I wish to acknowledge the work of the members of the Task Force and in particular its Chair, Christy Lynch, whose vision and commitment brought this report to fruition. I would also like to commend the work of the Advisory & Consultative Groups, ably chaired by Siobhan Barron. Their dedication, and that of the wider Task Force, has ensured that the person is placed at the centre of the decision making process and that the independence and choice of the individual are respected.

I would also like to pay tribute to the late Martin Naughton who was appointed to the Task Force but sadly passed away before being able to participate. Martin was a tireless advocate for people with a disability and his campaigning over many years put the issue of personalised budgets firmly on the public policy agenda. The publication of the Task Force Report marks a significant milestone in enhancing choice and person centred support which Martin always advocated for.

I fully endorse this Report, and was delighted to present it to Government for approval. I look forward to the proposed models being road tested without delay and the learnings from the demonstration sites informing the roll out of personalised budgets.

Finian McGrath, T.D.

Minister for Disabilities

CHAIRMANS FOREWORD

The Program for Government in 2016 included a commitment to the establishment of a task force on personalised budgets for people with disabilities. The Task Force was established by Minister Finian McGrath, TD on 20th September 2016. The remit of the Task Force was focussed on giving people with disabilities more choice in accessing health-funded personal social services. From the outset, the Task Force set about its work in an open and transparent way and minutes of all meetings, documents and the work plan were posted to the Department's website. It was important to learn from the international/Irish experience regarding the utilisation of personalised budgets by people with disabilities. In this regard, a number of Irish projects presented to the Task Force and a comprehensive review of the international literature was undertaken.

The structure of the Task Force comprised of a Strategy Group and an Advisory and Consultative Group, supported by a Reference Group. This ensured a wide range of perspectives and most importantly the lived experience of people with disabilities and their family members. A detailed work plan was developed at the outset and the Task Force members made available their knowledge, expertise and experience to progress this.

In late 2017, when the work was at a reasonably advanced stage, we held four consultation meetings across the country in Dublin, Cork, Galway and Cavan. We also launched a Public consultation inviting submissions from any interested party to submit their views to the Task Force. Both the meetings and the Public consultation provided us with a wealth of additional information and views which assisted us in our task. I would like to thank all those who took the time to attend the meetings and/or make a written submission.

From the feedback to the public consultation, it was striking to see the excitement and enthusiasm for the opportunities that a personalised budget could offer. This was however balanced with some amount of trepidation around what would be involved in managing a personalised budget. If accepted by Government, I hope that the work of the Task Force, and the framework for personalised budgets that it recommends, will provide enough clarity for people to consider a personalised budget as a real alternative to a traditional service model.

Building on the review of evidence and consultations carried out by the Task Force, the report advocates three different models of how personalised budgets might be accessed by people with disabilities.

1. Person-managed fund, often referred to as Direct payments
2. Co Managed With the service provider
3. Broker managed fund

The rationale for several models is a recognition of the fact that no two people are the same and therefore, 'One size does not fit all'. We recommend that each of these models be tested and evaluated within two years of the publication of the Task Force Report to inform a wider roll out of personalised budgets in Ireland.

As Chairman, I want to extend my sincere thanks to every member of the Task Force for their hard work, dedication and commitment to ensuring that people with disabilities have more choice and control as to how they are supported. I would also like to thank the Secretariat who I worked closely with for the duration of the Task Force for their valued support, dedication and attention to detail throughout the process.

It is clear from the international evidence that personalised budgets are not a panacea and not for everyone with disability. It is also clear that for those who chose to avail of a personalised budget they have significant choice and control and therefore have been able to live the life of their choosing and realise their personal dreams and ambitions. The learning both from the international evidence and the views expressed from the wide ranging consultation was that there are many other areas of Public Service where personalised budgets could be utilised. I am confident that the work of the Task Force has laid a strong foundation to introduce personalised budgets in Ireland. As with any foundation it is my hope that this will continue to be built on which will assist in ensuring a better quality of life for people with disabilities in Ireland.

Christy Lynch

Chair of the Task Force on Personalised Budgets

EXECUTIVE SUMMARY

Context

Personalised Budgets are becoming increasingly popular internationally as a way of providing individuals with more choice and control over the services and supports they access. The Programme for Partnership Government (2016) contained a commitment to the introduction of personalised budgets for persons with disabilities.

In general a personalised budget is an amount of funding which is allocated to an individual by a state body so that the individual can make their own arrangements to meet specified support needs, instead of having their needs met directly for them by the State.

Personalised budgets are optional and people with disabilities may choose to retain traditional services from the HSE or a HSE funded service provider.

The Task Force on Personalised Budgets

The Task Force was established by the Minister of State for Disabilities, Finian McGrath T.D. on 20 September 2016, on foot of a commitment in the Programme for Partnership Government.

The Task Force on Personalised Budgets consists of a Strategy Group and an Advisory and Consultative Group. Its remit was to make recommendations on potential models of personalised budgets, which will give people with disabilities who wish to avail of a personalised budget more control in accessing health funded personal social services, giving them greater independence and choice in accessing services which best meet their individual needs. A Reference Group comprising people with lived experience of disability and disability services was also established, and the views of this group informed and influenced the final report of the Task Force.

The remit of the Task Force was to consider HSE Disability Service-funded person social services and supports for all adults It does not include clinical services currently provided by the health services (such as medical services and therapy supports), or general living expenses. The Task Force worked with the aim of developing a system that can evolve and grow to meet additional areas of expenditure over time.

Visions and Principles guiding the Task Force

The Task Force had a clear vision for people who may want to use a personalised budget. That vision was that personalised budgets will enable a person with disabilities to have choice and control over individualised supports in all aspects of their lives, to live an independent life and to be an active participant in their community.

The Task Force also felt that a personalised budget should embody the key principles of: choice; dignity, empowerment, equality, independence, person-centredness, and respect.

Research findings

The Task Force undertook a detailed work programme to enable it to make evidence-based proposals. An in-depth international evidence review supported by work done previously by the HRB and the NDA gathered information on different forms of personalised budgets in other countries including the people who were eligible, and the types of supports and services that were available. The challenges, successes and obstacles experienced in these countries helped the Task Force to refine its proposals.

Research has shown that better outcomes, such as an enhanced feeling of well-being on the part of budget holders, are achieved, but it should be noted that there has been little formal evaluation of personalised budget systems in other countries. However, international experience did draw attention to the risk of increasing expectations and new demand, leading to higher costs if not carefully managed. Transaction costs such as implementation costs, costs of commissioning or arranging services must also be considered when introducing personalised budgets. International evidence highlighted the need for transitional and set-up funding to develop new systems, train staff and to test and evaluate the new processes.

The review of personalised budgets in other countries was complemented by information gathering on a small number of existing approaches to individualised funding in Ireland.

The Task Force also undertook a public consultation process that gave depth to their understanding of what people expected from a personalised budget, what it might involve and what supports they would need to use one.

The model proposed

Based on the outcomes of the work programme, and the deliberations of the members, the Task Force took the view that a personalised budget model should follow the process set out below:

Before PB: **Assessment of Support Needs** - People in receipt of services or supports funded by HSE Disability Services, or looking to receive such supports or services, are assessed using a standardised assessment process and a resource allocation tool. They would also identify their needs and desired outcomes through a person-centred planning process. This would form the basis for an indicative budget, which the person may then choose to use to avail of in the form of a personalised budget.

Stage 1: **Information on Supports Options** – the person engages in an information and briefing stage to determine if a personalised budget is likely to be suitable for them. This means that the person is fully informed of the benefits, risks, opportunities and responsibilities of a personalised budget before choosing to avail of one.

Stage 2: **Application** – The person applies for a personalised budget and works with an assessing practitioner to outline a Personal Support Plan (PSP). This outlines what funding and supports are available.

- Stage 3: **Support & Planning** – Any queries raised by the person are addressed and each of the three payment options would be discussed (Person Managed Fund; Co-managed with Service Provider; Broker Managed).
- Stage 4: **Implementation and Accountability** – The person decides on their preferred payment model option for a personalised budget. The person finalises their personal support plan, in consultation with a Liaison Officer, a Service Provider or a Broker.
- Stage 5: **Review & Governance** – The review stage involves a review of both the person’s experience of a personalised budget and the outcomes achieved, as well as a financial review to ensure that the money is being spent in line with the support plan. Adjustments to the personal support plan, the payment option selected, or the funding level can be made at the review stage. A person may also choose to go back to a traditional service provider if they find that a personalised budget does not work for them.

Conclusions

The Task Force has identified that comprehensive guidance will need to be developed to support people through the process of considering and applying for a personalised budget. It is also recommending that a standardised assessment tool be put in place under which a selected resource allocation tool can be used to quantify support needs. These tools will help people to make an informed decision about whether a personalised budget will work for them.

The Task Force came to the conclusion that the final design of any system of personalised budgets in Ireland can only be decided upon once a series of initial demonstration projects have been evaluated and the findings assessed, alongside the outcomes achieved by the person and the financial sustainability of the system as a whole.

Recommendations

The Task Force has produced 18 recommendations which outline the overarching framework for the introduction of personalised budgets in Ireland under thematic headings which included: National Framework for Personalised Budgets, Operation of Personalised Budgets, Supports for Individuals, Demonstration Projects, and Additional Considerations. These recommendations are wide ranging and encompass the assessment process, the infrastructure and supports required for personalised budgets, the governance process, and the actions to be taken by Government. The Task Force also makes the case for initial demonstration projects to test a range of issues such as different payment options, the costs of operating a personalised budget for the individual, quality assurance, employment issues, and financial sustainability in the Irish context.

VISION STATEMENT

Personalised budgets will enable a person with disabilities to have choice and control over individualised supports in all aspects of their lives, to enjoy an independent life and to be an active participant in their community.

SUMMARY OF RECOMMENDATIONS

National Framework for Personalised Budgets

1. A personalised budget may be used for support with daily living activities and participation in the community, including personal assistance or home care support.
2. A personalised budget should not duplicate any supports or services provided by another Department or Statutory agency or be used for day to day living costs such as rent, groceries, utility bills or other consumer spending.
3. The personalised budget arrangements will allow for three possible funding models:
 1. Self-managed fund/ Direct payment
 2. Co-managed with HSE/Service Provider
 3. Broker/Intermediary managed.

Operation of Personalised Budgets

6. Funding should be approved on the basis of a standardised assessment of individual need. A profiling tool should be selected for use in the initial demonstration projects.
4. The operation of personalised budgets, following a standardised assessment of the individual's needs, will follow the five stages outlined in Chapter 6 of this report i.e.
 1. Information and Support
 2. Application
 3. Support and Planning
 4. Implementation and Accountability
 5. Review.
5. The governance of personalised budgets will follow the guidelines outlined in Chapter 7 of this report. The level of governance will vary depending on the funding option and on the amount of the personal budget approved.
7. Following notification of indicative budgets a detailed spending plan will be agreed by the assessing practitioner and the applicant (and their family or other support network as appropriate), as to how their support needs will be met.
8. This support plan will take into account the natural supports that are provided through family, community or other state supports. The final personalised budget may vary from the indicative budget based on the outcome of this planning process.

Supports for Individuals opting for personalised budgets

9. A standardised training package should be made available on the various elements of managing a personal budget. Training should include a focus on HR law, finance, employment relations etc.

Demonstration Projects/Testing Phase

10. A key action in moving to personalised budgets is to undertake a planning and testing phase. The Department of Health and the HSE should establish demonstration sites to test the delivery of personal budgets (e.g brokerage models, direct payments, etc.) with a view to identifying the best approach to the wider roll-out of these payment models following the initial demonstration phase.

11. The demonstration projects should also test a range of issues such as the costs of operating a personalised budget for the individual, quality assurance, employee management issues, governance arrangements and financial sustainability in the Irish context in accordance with the recommendations of the Task Force outlined above.

12. The demonstration projects should be implemented over a two year period from the date of publication of the Task Force Report.

13. A formal evaluation of the Demonstration Projects should be completed and submitted to the Department of Health at the end of the two year period.

14. The Department of Health should assess the evaluation report and make recommendations to Government on the next steps regarding roll out of personalised budgets.

Other

15. Learning from the demonstration sites should inform the development of guidelines required to enable further implementation of a personalised budgets system. This should include specific provisions to support the introduction of a direct payment model of personalised budgets and graded levels of accountability.

16. In conjunction with the Department of Employment Affairs and Social Protection, the Department of Public Expenditure and Reform and the Department of Finance, the Department of Health should examine whether legislative change may be required to ensure that a personalised budget is not subject to assessment as income or means-tested for the purposes of the Finance Acts or Social Welfare Acts, or for other income tested schemes.

17. The Department of Health should report progress on the development and implementation of personalised budgets under the National Disability Inclusion Strategy.

18. The outcomes of the demonstration projects should be shared with other Government Departments, who may wish to consider the potential to implement personalised budgets in their sector.

GLOSSARY

Accountability

Accountability is the obligation to accept responsibility for, and to account for your actions, and to disclose the results of those actions in a transparent manner.

Public bodies are accountable to their stakeholders and must be able to demonstrate that their policies and programmes achieve the intended result, and that they use their resources effectively to achieve their stated goals.

Accessibility

For people with disabilities, accessibility means having access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services which are open to, or are provided to, the public, both in urban and in rural areas. Accessibility is essential to enable people with disabilities to live independently and participate fully in all aspects of life.

Activities of Daily Living

Activities of Daily Living are the things people do every day to look after themselves, such as washing, dressing, eating, going to the bathroom, walking and moving about (particularly getting in and out of bed, or sitting and standing).

Advocacy

Advocacy is a process of supporting and enabling people to express their needs and wishes; access information and services; weigh up decisions; explore their options; deal with service providers; defend and promote their rights and responsibilities.

An independent advocate is someone who is separate to a service provider or family, and who represents their client's will and preferences. The advocate's role is to support an individual to speak for themselves, or to speak on their behalf.

Self-advocacy is when an individual speaks up for themselves and makes their needs and wishes known and their views heard. Some family members or representative bodies can also take on an advocacy role for an individual.

Assessment of need

The process to identify the support needs of an individual with a disability. Depending on the context, it can also refer to assessments of the care needs of other groups, such as older people or people with mental health needs.

In the case of a person with a disability born on or after 1st June 2002, an assessment of need means a statutory assessment process which involves a number of different health professionals and covers the full range of the child's needs, including the need for therapies.

In the case of adults, a reference to an assessment of need usually refers to a measurement of the individual's social care needs only – an adult's therapy needs are evaluated separately. . Following an assessment of need, support needs can be quantified using an agreed resource allocation tool.

Brokerage

Brokerage is a way of providing people with the information, support and guidance they need to plan, arrange for and manage their supports and services.

Brokers must be independent, and must operate in the best interest of the individual who has asked for their support. Brokerage can be provided by people or organisations who specialise in brokerage only, or through service provider organisations.

Assisting a budget-holder to work out the services and supports which best meet their needs and preferences, and to obtain these services within their available resources is a core feature of brokerage, but apart from that the range of services provided by brokers varies as well as the duration and type of support provided. The ways in which brokerage is funded also vary.

Capacity

Decision-making capacity is the ability to understand, at the time that a decision is to be made, the nature and consequences of that decision. Everyone is assumed to have decision-making capacity unless it is proven otherwise. People may have the capacity to make some decisions but not others, or to make decisions at certain times but not at other times.

A person has capacity to make a decision if they are able to understand the information relevant to the decision; retain that information long enough to make a voluntary choice; use or weigh that information as part of the process of making the decision; communicate the decision in whatever way they can (not only verbally) . The Assisted Decision Making (Capacity) Act of 2015 provides a legislative framework for presuming and supporting decision-making capacity.

Choice

To make an informed choice, a person needs to build up a picture of the available options before comparing the advantages and disadvantages of each. The information needed to support informed choice should be accessible, understandable, relevant and of high-quality.

Circles of Support

A Circle of Support is a small group of people who have a personal relationship with a person with a disability (often called the focus person) and who meet together on a regular basis to support that individual in achieving their life goals. The focus person is in charge, decides who to invite into the Circle, and what goals he or she needs the Circle to support. The members of the Circle of Support may include family, friends and other community members, acting in a voluntary capacity.

Commissioning

Commissioning can refer to a complex process carried out by an organisation in respect of the present and future support needs of a large group of people, or it can refer to a more straightforward and immediate process of obtaining services for one individual person.

Commissioning by an organisation is a longer term strategic planning tool that aims to link resource allocation with critical policy objectives, such as value for money; meeting present and future needs; quality improvements; service user outcomes.

Commissioning by, or on behalf of, an individual means selecting and securing support services for that individual.

Direct payment

A payment, which may be in the form of cash, which is made directly to someone in need of support to allow the person greater choice and flexibility about how their supports and services are delivered.

Eligibility

Eligibility means satisfying the conditions necessary to participate in a scheme or programme or receive a benefit.

General living expenses

General living expenses in the context of personal budgets are the same type of expenses that a person without a disability is reasonably expected to meet from their own resources. These include utility bills, like electricity, gas, telephone etc; food and drink; household goods; mortgage or rent; insurance.

Governance

Governance is the way in which the rules, processes and actions of a project, programme or an organisation are structured, regulated and held accountable.

In the case of organisations, the principles underlying corporate governance are based on conducting the business with integrity and fairness, being transparent with regard to all transactions, making all the necessary disclosures and decisions and complying with all the laws of the land.

HSE-funded disability services

The term “HSE-funded disability services” is intended to be a type of shorthand for the broad category of personal social services and supports which the HSE funds from its budget for specialist disability services by its Disability Services Division. Services which are funded by other Divisions within the HSE, or by other Government Departments, are not part of the Task Force’s remit.

Independent living

Independent living means the equal right of people with disabilities to live in the community, with choices equal to others, and to have their full inclusion and participation in the community supported.

Individualised Budgeting

Individualised budgeting is an umbrella term that may take many forms, ranging from a method of determining resource allocation to agencies based on assessed client need and actual costs, to a “money follows the client” model, a brokerage system or a personal budget model administered by the individual service user. With individualised budgeting, the main transfer to the service user is the transfer of choice and control over funding decisions. This might or might not involve the transfer of actual funds to the individual.

Personal Supports Plans

A personal support plan is a statement of the supports and services required by a person with disabilities, based on their needs and goals. The service user should be at the centre of the process used to define the support plan, which considers all forms of support; from those available within the family, other informal forms of support to more formal services.

Outcomes

Outcomes are the effects on the individual of the services or supports received. Outcomes may be influenced by factors other than quality of services, such as the individual’s level of adaptive ability, degree of disability, personal characteristics, or medical condition. Some outcomes may be experienced on a short-term basis while others may be long-term or even permanent.

Person-centred planning

Person-centred planning is defined as a way of discovering how a person wants to live their life, and what is required to make that possible. In person centred planning the primary focus is on the person, not on a disability or on a particular service.

Person centred planning is separate to an assessment of need process or development of a service plan, and may be developed either within services or entirely independently of them. In either case, it is the individual or family who decides whether to develop a person centred plan, how it is developed and whether to pursue it once it is developed.

Personal Assistant

A Personal Assistant (PA) provides the person with a disability with one to one assistance with a range of daily activities, both inside and outside the home, as determined and directed by the individual service user. The purpose of personal assistance is to promote choice and control, to empower the person with a disability, and to enable him/her to live an independent life in his/her home and community. The person who avails of the PA’s services is often referred to as the Leader.

Personalised Budget

Generally speaking, a Personalised Budget is an amount of funding which is allocated to an individual by a State Body so that the individual can make their own arrangements to meet specified needs, instead of having their needs met directly for them by the State.

By availing of a personalised budget the individual has greater choice and control over the way in which their needs are met, compared with direct service provision.

In the case of the Task Force on Personalised Budgets, a personalised budget is an amount of funding which would be paid from the HSE's budget for disability services and provided to an eligible person with a disability to meet their needs for personal social services and supports.

With a personalised budget, the person with a disability would use their budget to make their own arrangements to obtain the supports or services of their choice, instead of having those services identified for them by the HSE and provided for them directly by the HSE or a HSE-funded agency.

Quality assurance

This is a systematic way of monitoring and evaluating the various aspects of a project, service, or facility to ensure that standards of quality are being met.

Resource allocation

Resource allocation provides a way of calculating a funding package which is based on an assessment of an individual service user's needs. The allocation of resource has to reflect the needs of the individual but will also (usually) be constrained by the budgets of funders, and so the resource allocation system can also act as a way of balancing these two factors.

Risk Assessment

A systematic process of evaluating the potential risks that may be involved in a project or system.

Support workers

Workers whose job is to assist people with home support, personal support, and other types of one-to-one assistance.

Sustainability

Sustainability in the public sector refers to the ability of an organisation to continue performing efficiently and effectively to achieve its stated goals over the long term within the resources available to it.

Unbundling funding

Funding for disability services has traditionally been provided in a block grant to a service provider based on the total number of people using the service rather than the actual cost of each person. Switching to personalised budgets means that the cost of the service to an individual would need to be calculated and separated or "unbundled" from the overall grant paid to their current service provider. How to achieve unbundling of funding in the future will need to be examined carefully by the HSE.

1 Introduction: Background and Context

1.1 Background and Context

Personalised budgets are becoming increasingly popular internationally as a way of providing individuals with more choice and control over the services and supports they access. The Programme for Partnership Government contained a commitment to introduce personalised budgets for persons with disabilities.

In general a Personalised Budget is an amount of funding which is allocated to an individual by a state body so that the individual can make their own arrangements to meet specified support needs, instead of having their needs met directly for them by the State.

By availing of a personalised budget the individual has greater choice and control over the way in which their needs are met, compared with direct service provision.

Applications for a personalised budget are optional and people with a disability may retain traditional services via the funder or a funded service provider. The amount of funding made to an individual available under a personalised budget should not exceed the funding that would be available under a traditional service provider model.

The introduction of a personalised budget for individuals with disabilities is mentioned in the report of the Committee on the Future of Healthcare – Sláintecare, which suggests that personalised budgets would empower service users and families to be key decision makers in how services are provided¹.

1.1.1 Establishment of Task Force

The Task Force was established by the Minister of State for Disabilities, Finian McGrath T.D. on 20 September 2016, on foot of a commitment in the Programme for Partnership Government. The remit of the Task Force was to make recommendations on a cost-neutral approach on a personalised budget model that will provide individuals with disabilities more control and choice in accessing health funded personal social services. While the concept of personalised budgets is not limited to health and personal social services, Government agreed that the Task Force should focus on services for adults with disabilities funded by HSE Disability Services i.e. health and social care. This is reflected in the Task Force's Strategy Group's Terms of Reference, which clearly outline the objectives of the Task Force.

¹ "Further work is needed to cost universal services for people with disabilities, which respect the autonomy of service users and their families as well as empowering them to be the key decision makers in how services are provided. There is a movement towards personalised budgets for people with disabilities. Further work is needed on costing and changing to such a model of care. In the meantime it is essential that services are developed to better meet the needs of people with disabilities and their families." *Sláintecare Report*. Houses of the Oireachtas Committee on the Future of Healthcare. May 2017 p. 67.

1.1.2 Task Force Terms of Reference for Strategy Group

- To consider the key elements of a framework for implementing personalised budgets with an initial focus on HSE-funded personal social services including: an effective application process; assessment of need; eligibility; scope of supports and services that could be funded with such budgets; governance and accountability; supports to individuals and families to avail of personalised budgets (e.g. brokerage, other administrative supports, information etc.) and how these elements can be operationalised; as well as any implications of a programme of personalised supports on services and supports for persons with disabilities;
- To consider the learning from current personalised budgets initiatives in this country and advise on the case for development of a pilot with inbuilt evaluation in order to test recommendations and provide learning for national roll-out;
- To consult with relevant stakeholders and civil society;
- To present a report outlining recommendations for a national system of personalised budgets, infrastructure and next steps;
- To consider and review options for sustainability of recommended approaches.

1.1.3 Mission Statement

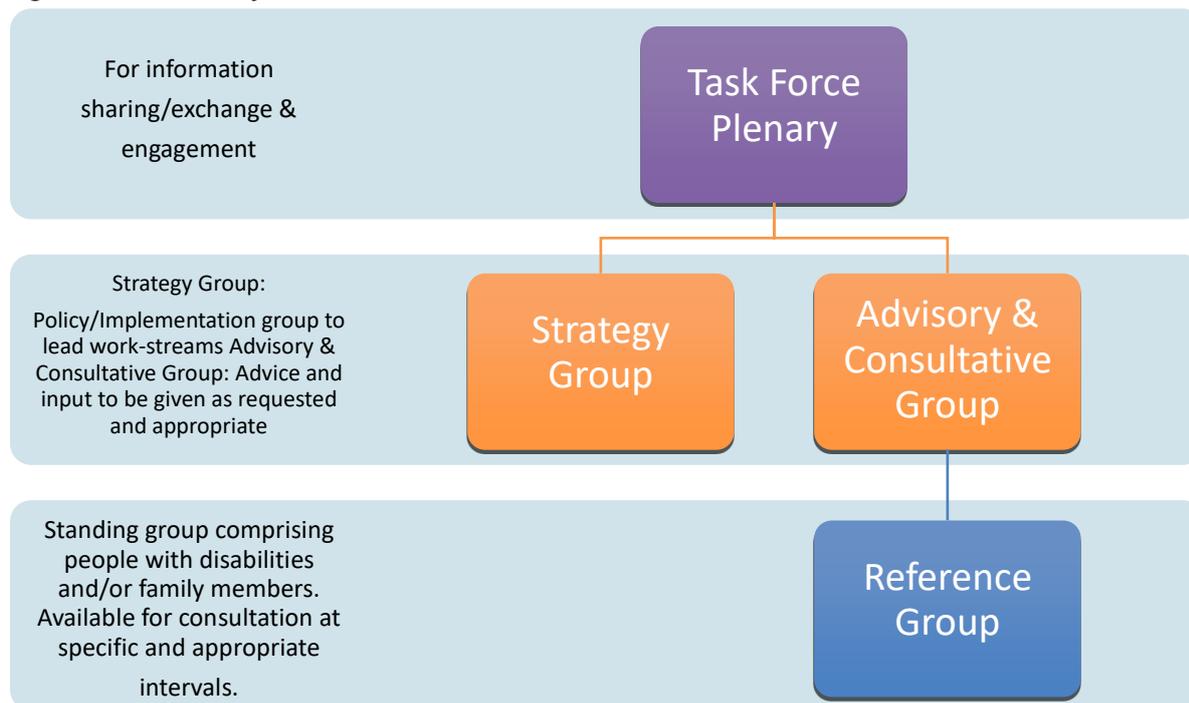
The Task Force's mission is to make recommendations on an approach and a suggested implementation strategy for Government's consideration, on the introduction of a system of personalised budgets in Ireland for HSE-funded personal social services and supports for people with disabilities. This will be done in keeping with other commitments and aspirations within the Programme for Partnership Government – both economic and social.

1.1.4 Task Force Structure

The Task Force has two main components:

- Strategy Group, responsible for leading the development of recommendations and implementation pathways for the Task Force as a whole (hereafter the Strategy Group);
- Advisory & Consultative Group, responsible for delivering advice and input as requested on key items arising during the work of the Strategy Group.

Figure 1: Overview of Task Force structure



1.2 Scope

The work of the Task Force was to consider personalised budgets in the area of HSE-funded personal social services and supports. Wider supports such as education and employment were outside the remit of the Task Force. The needs of an individual with disabilities stretch beyond supports offered within healthcare alone and recognising this, the Task Force adopted an approach to the development of personalised budgets which could be shared with other State-funded services for people with disabilities in the future. It should be noted that any decisions in this regard are outside the scope of the Task Force.

The Task Force encompasses all adults in receipt of, or becoming eligible for, HSE Disability Service-funded personal social services and supports². The Task Force will consider people whose primary disability is physical or sensory, intellectual, autism, neurological or any combination of these. It does not include clinical services currently provided by the health services (such as medical services and therapy supports), or general living expenses. The Task Force is working with the aim of developing a system that can evolve and grow to meet additional areas of expenditure over time.

The Task Force decided upon seven work streams to inform its deliberations:

² This includes those whose primary disability is physical or sensory, intellectual, autism, neurological or any combination of these.

Table 1: Task Force Work Streams from Project Initiation Document

Work stream	Title	Description
1.	Discovery phase	Identify the key questions on which information and evidence is required to guide its consideration of the different items in the Terms of Reference; Collate the results of research to date under each of the key questions (e.g. HRB evidence review, NDA research etc.).
2.	Eligibility / Resource Allocation	Scope of services and supports to be covered by personalised budget option in a first phase of rollout, subject to resources; Eligibility criteria and how they will be defined and assessed.
3.	Financial Sustainability	What mechanisms are in place in other jurisdictions to address financial sustainability; Issues to be considered with regard to decoupling funding from existing service providers where this applies; Identification of current level of resourcing and potential availability for redeployment; Need for funding to manage transition between personalised and traditional approaches.
4.	Supports to apply for and administer budgets	Analysis of supports required, including information infrastructure; brokerage system and back-office services; support to prepare applications; supports for individual administration, accounting, payroll, timesheets, human resources, etc.
5.	Governance and Accountability	Propose administrative and governance framework.
6.	Appraisal	Appraise each option (benefits, risks, costs etc.); Develop a final report on the work of the Taskforce with recommendations for review and decision by Government.
7.	Implementation Plan	Develop suggested timeline and pathway towards implementation, including transition arrangements between models or approaches.

Source: Task Force Project Initiation document (full text at [Department of Health](#))

1.3 Methodology

The report that follows sets out the views and recommendations of the Task Force, based on a series of inputs it considered under the various headings in the work-plan. Under each heading, the Strategy Group reviewed information on the main issues and concerns that would need to be addressed when recommending a national approach to a system of personalised budgets. The original material considered is available on the Department of Health website, and this document offers a summary of the main points together with the output of the Task Force discussions. The data includes research work conducted by HRB and NDA among others, presentations on personalised budgets and pilot projects carried out in Ireland, discussion documents presented by members of representative bodies, and a technical process map prepared by a contracted consultant.

The Strategy Group reviewed all of the material provided and discussed in detail relevant information arising. Following its meetings materials were circulated to the Advisory Group for their consideration and discussion. Consideration was also given to ensuring that the papers provided were accessible and that the Advisory Group had sufficient time to consider documentation and revert with observations to the Strategy Group.

In this way, a consolidated view of the appropriate next steps was developed by the Task Force. It is acknowledged that there were some areas in which the views of members of the Task Force differed. These areas are recorded in this report. The preliminary views of the Task Force were further informed by a public consultation exercise, which took place during October 2017.

The Task Force met in plenary session on three occasions over 2016 and 2017. At the second plenary session in 2017, the Task Force agreed the overarching vision for its work and the main headings of the final report, based on the outcome of the discussions held by both the constituent groups over the year. The Task Force met a final time in 2018 to review and agree the final draft of the report. At these two later meetings, it was also agreed that areas noted by Task Force members as being important for future consideration, but which were beyond the original remit of the group, would be recorded in a note to accompany the final report on its presentation to the Minister.

A full overview on the methodology is available at <http://health.gov.ie/disabilities/task-force-on-personalised-budgets/>

1.4 Policy Context

The introduction of personalised budgets should be considered in the context of the wider reform programme currently underway within disability services in the HSE. In the last decade, there has been an increased interest in person-centred services. It is important to note some of the key policy shifts underpinning the move towards individualised funding and personalised budgets briefly here:

1.4.1 Transforming Lives Implementation

The Transforming Lives Programme is a national collaborative effort to build better supports and services for people with disabilities. Transforming Lives promotes inclusion and values the self-determination of people with disabilities while respecting their rights by promoting maximum independence and self-determination.

The programme is based on a number of key policy documents³ and is underpinned by legislation⁴ to ensure that people with disabilities are supported to exercise choice and control and make significant decisions in their lives.

1.4.2 Value for Money and Policy Review of Disability Services – individualised funding

The Value for Money and Policy Review of Disability Services defines Individualised budgeting as “an umbrella term that may take many forms⁵”. Individualised budgets may or may not involve the transfer of actual funds to the individual. The Review also notes that “it would not be advisable to move to a fully individualised budgeting system until the necessary availability of alternative service options had been properly piloted, tested and sufficiently established so as to avoid the creation of a vacuum in service quality. However, the balance and emphasis needs to shift firmly and comprehensively towards these new models of individualised supports... ”.

The Review notes that the movement towards individualised services and supports should adopt a common-sense incremental approach, which acknowledges capacity issues and financial constraints, but which is directed towards the achievement of the vision, goals and objectives of the Review, as now encompassed under Transforming Lives.

1.4.3 National Framework for Person Centred Planning for Disability Services

A National Framework for Person Centred Planning is currently being developed by the National Disability Authority under the New Directions Implementation Programme. The framework is intended to inform and guide how person-centred planning is implemented across all services for persons with a disability in Ireland. The framework provides a clear picture of what good practice looks like and aims to support individuals, teams and organisations to identify areas for improvement. The Framework supports positive outcomes for persons with a disability through promotion of good practice in person centred planning.

1.4.4 Wider Policy Considerations

There are a number of policy changes for the disability sector as a whole that will also impact on the implementation of personalised budgets:

Ireland recently ratified the *United Nations Convention on the Rights of Persons with Disabilities*. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. It requires an approach to services which puts the person’s civil and human rights first. Significant administrative and regulatory barriers to ratification were identified and are being progressively addressed through, for example, the Assisted Decision Making (Capacity) Act, 2015.

³ Department of Health Transforming Lives –Value for Money and Policy Review of Disability Services; HSE New Directions- Personal Support Services for Adults with Disabilities; HSE Time to Move on from Congregated Settings.

⁴ Disability Act 2005 and the Assisted Decision-Making (Capacity) Act 2015.

⁵ “... ranging from a method of determining resource allocation to agencies based on assessed client need and actual costs, to a ‘money follows the client’ model, a brokerage system or a personal budget model administered by the individual service user. With individualised budgeting, the main transfer to the service user is the transfer of choice and control over funding decisions. This might or might not involve the transfer of actual funds to the individual”.

The National Disability Inclusion Strategy (2017-2021) was launched by Minister Finian McGrath in July 2017. This Strategy captures a wide range of actions across Government Departments that will impact on the lives of people with disabilities and is to be viewed as a blueprint for an inclusive, accessible and equal country that incorporates issues that affect quality of life, health, education and transport. One of the key actions under the NDIS is the commitment to report on the work of the Task Force towards introducing personalised budgets.

The Assisted Decision Making (Capacity) Act was signed into law on the 30th December 2015. This Act applies to the whole of society and therefore is relevant to decisions regarding accessing all health and social care services. The Act supports maximising an individual's decision making capacity and will have significant implications for health and social care providers in the provision of safe person-centred care.

1.5 General Eligibility for Health Services

The Irish Public Health System provides for two categories of eligibility for persons ordinarily resident in the country, i.e. persons with full eligibility (medical cardholders) and persons with limited eligibility (all others).

1.5.1 Persons with full Eligibility

Such persons are entitled to a range of services including general practitioner services, prescribed drugs and medicines, all in-patient public hospital services in public wards including consultants services, all out-patient public hospital services including consultants services, dental, ophthalmic and aural services and appliances and a maternity and infant care service. Other services such as allied health professional services may be available to medical card holders. With the exception of prescribed drugs and medicines, which are subject to a €2.00 charge per prescribed item (maximum of €20 month per month per individual/family), these services are provided free of charge.

Full eligibility is determined mainly by reference to income limits. However, in June 2017 person's for whom a domiciliary care allowance payment is made are automatically entitled to a medical card.

1.5.2 Persons with Limited Eligibility

Persons with limited eligibility are eligible for in-patient and outpatient public hospital services including consultant services, subject to certain charges. The public hospital statutory in-patient charge is €80 per day up to a maximum payment of €800 in any twelve consecutive months. There is also a charge of €100 for attendance at Accident & Emergency departments unless, inter alia, the person has a referral letter from their General Practitioner.

Persons with limited eligibility must meet the first €134 of prescribed medicine costs per month, above which the Drug Payments Scheme meets all further costs. Dental and routine ophthalmic and aural services are not provided by the State, but this treatment is provided to children who have been referred from a child health clinic or a school health examination. A free maternity and infant care service is provided during pregnancy and up to six weeks after birth. Other services such as allied health professional services may be available to persons with limited eligibility. The Irish Public Health System provides for two categories of eligibility for persons ordinarily resident in the country, i.e. persons with full eligibility (medical cardholders) and persons with limited eligibility (all others).

It should be noted that, in the case of Disability Services, specialised services are provided on the basis of need and are effectively provided free of charge except in the case of contributions that apply under the Residential Support Services Maintenance and Accommodation Contributions legislation or where there has been a financial settlement to cover the cost of care.

1.6 Disability Services funded by the HSE

This section provides a short overview of the main HSE funded disability services and supports that people with disabilities currently avail of in the area of personal social services. It does not therefore cover the areas of support currently funded by other Government Departments and agencies e.g. training, education, employment supports, housing supports etc.

Funding of €1.772 billion was allocated by the Health Service Executive (HSE) for disability services in the National Service Plan 2018.

Table 2: HSE Disability Services funding

Disability Services Programme: €1.772 billion 2018	Quantum of Services
Residential services	9,000 people
Day services	Over 24,000 people
Respite and residential support	182,500 overnights
Personal Assistant services	1.46 million hours
Home Support services	2.93 million hours
Target to move from institutions to homes in the community in 2018	170 people

Source: HSE National Service Plan 2018

Pay costs account for 82-85% of this expenditure. The largest components of HSE disability expenditure are residential care and day services (68% and 21% respectively). Expenditure on elements such as respite care, personal assistance, home support services and community-based allied healthcare professional services, form a small part of the total spending (together, they constitute approximately 11%, or €195 million, of total spend). This is worth noting as this last group are the services most typically included in models of personalised budgets that have been introduced internationally.

1.7 Conclusions

The implementation of any system of personalised budgets should be aligned with the spirit and structures of the wider policy framework and the Assisted Decision Making (Capacity) Act 2015, and, in particular, in the presumption of capacity for all people with disabilities.

2 National and international experiences

2.1 International experience of personalised budgets

As there has been very limited experience of forms of personalised budgets in the Irish context, much of the information available to the Task Force came from evidence of personalised budgets in other jurisdictions.

2.1.1 HRB individualised budgeting for social care services for people with a disability: International approaches and evidence on financial sustainability

The first of these was a report commissioned by the Department of Health and carried out by the Health Research Board (HRB) on ‘individualised budgeting for social care services for people with a disability: International approaches and evidence on financial sustainability’⁶. This work preceded the establishment of the Task Force and informed the Project Initiation Document and subsequent work of the Task Force. In reviewing the practical details on the operation of personalised budgets in other countries, it was useful to examine the criteria for determining eligibility for a needs assessment and the entitlements that follow a needs assessment, financial limits set on service provision and mechanisms adopted in other countries to ensure financial sustainability. The review focused predominantly on six selected countries- Australia, Canada, England, the Netherlands, New Zealand and Scotland.

The HRB Evidence Review noted that the introduction of Personalised Budgets is still “a work in progress” with personalised budget schemes only recently introduced or significantly revised in recent years in many countries. As such, the HRB Evidence Review highlights a lack of evidence regarding the financial sustainability of Personalised Budgets and notes that any comparisons or conclusions are rendered more difficult when one considers that varying contexts, economic models and systems in the countries examined. However, a number of common issues emerged in the HRB Evidence Review which can be used to inform the planning, implementation and monitoring of any system of personalised budgets in Ireland.

2.1.2 National Disability Authority (NDA) Synthesis Paper on Personalised Budgets.

The NDA had previously progressed work on individualised funding in the context of the Value for Money and Policy Review of Disability Services in Ireland, including facilitating round-table discussions with a range of stakeholders and carrying out a rapid evidence review of experiences in other jurisdiction. The NDA has previously carried out a review of resource allocation systems in order to inform the Department of Health and HSE in their decision regarding a national approach to this matter. Based on this work and a range of other inputs, the NDA prepared a synthesis paper for the Task Force, drawing from a number of the key research papers relating to personalised budgets both in Ireland and in other jurisdictions. While the majority of the research indicated that personalised budgets were introduced relatively recently in the jurisdictions covered, and therefore had not been

⁶ http://www.hrb.ie/uploads/tx_hrbpublications/Individualised_budgeting_for_social_care_2016.pdf

robustly evaluated in terms of costs or outcomes, several common findings emerged. The research indicated that a personalised budget model typically follows the process set out below:

1. An individual budget is calculated (through a variety of means) for an eligible person, indicating how much is available to spend.
2. Individuals, usually with a professional (a broker or care planner), identify their needs and desired outcomes through a person-centred planning process. This forms the basis for a spending plan, which must fit within the overall budget allocation.
3. The spending plan must be approved by the funding agency or a designated agent.
4. There is often choice as to how the budget is allocated – whether it is given as a direct payment to the individual; passed to a third party, to which the individual delegates responsibility for commissioning and purchasing the services; or retained by the commissioning organisation (as a ‘notional’ budget) to spend on the individual’s behalf. In some cases, an individual may be able to opt for a combination of these payment methods.
5. Individuals (or the agency managing the budget on their behalf) must then account for any purchases made against their approved spending plan

The NDA Synthesis Paper paper was drafted under four main headings:

- ***Eligibility and resource allocation***
- ***Supports to apply for and administer personalised budgets***
- ***Governance and accountability***
- ***Financial sustainability***

The review of international evidence on financial sustainability by the HRB and NDA was further supplemented by the Research Services Unit of the Department of Health in the context of Workstream 3 and additional information on this topic is presented under the Financial Sustainability section of this Chapter.

2.2 Eligibility and Resource Allocation

2.2.1 Eligibility

In countries with a personalised budget scheme, eligibility is determined either by individual application to the statutory agency or by statutory invitation for assessment. All countries have a citizenship or residency requirement. Half of the countries had an upper age limit of 65 while most countries have no lower age limit. In all countries, people with physical, intellectual, developmental and sensory disabilities were eligible and people with mental illness were eligible in most countries except New Zealand and some provinces in Canada. Disabilities have to be long lasting and have a significant impact on the life of the person with the disability. In some cases a personalised budget can be used to pay for long term residential care or fund early intervention or crisis support.

There are no studies evaluating the benefits of what is permitted spending in one jurisdiction compared to another. The review literature recommends flexibility in spending personal budgets as long

as it is achieving pre-agreed outcomes. The literature outlines concerns regarding paying family members but notes that there is very little evidence to support the concerns.

2.2.2 Allowed spending

The literature review identified specific areas of expenditure under a personalised budget that were permitted in all countries, in some countries, or that were not permitted at all. These limits were considered by the Task Force in forming its views on the types of supports that can and cannot be funded.

Table 3: Areas of spend allowed and not allowed in countries with a personal budget system

Allowed by all countries	Not allowed by any country	Allowed by some countries but not by others
<ul style="list-style-type: none"> • Employment of someone to provide personal care and support to participate in community activities 	<ul style="list-style-type: none"> • Things not related to the disability or that will not meet the supported person’s needs • Day to day living costs • Duplicates of other supports / supports provided by another source within the system • Anything illegal or causing harm or risk to others 	<ul style="list-style-type: none"> • Residential care • Respite care • Support for household management e.g. cleaning, cooking • Housing adaptation • Holidays • Day services • Transport • Paying family members

Source: Pike et al, 2016

2.2.3 Resource allocation

Resource allocation is ideally based on an assessment of need conducted by a practitioner (who knows the individual) or by self-assessment. The assessment should be client-led and outcomes-focussed and provide valid and reliable information on the individual’s needs and support systems that are in place. Resource allocations were assessed and reviewed annually or bi-annually in most cases. It was clear that transparency between assessment and subsequent resource allocations were complex and not always understood by the assessor. The research recognises that appeals processes operate in other jurisdictions, but does not provide much detail of how these processes are implemented. The literature reviewed recommended training for staff and assessors in relation to resource allocation and that any system adapted required flexibility to adapt to the supported person’s needs.

Between 2011 and 2015, the NDA conducted an extensive analysis of 4 resource allocation tools, and used this to inform advice to the Department of Health and HSE on the feasibility of introducing any one of these tools in an Irish context. It will be important for the implementation of any system of personalised budgets that a decision is made about the introduction of such a tool in a national standardised approach to resource allocation.

2.3 Supports to apply for and administer personalised budgets

2.3.1 Brokerage

The term ‘brokerage’ is used in a narrow sense to cover the facilitation of the development of a personal plan (independent of funders or providers) and in its broadest sense to cover a whole range of supports up to and including providing pay roll supports. There is almost no evidence-base on the effectiveness of brokerage. In the UK only a small percentage of people used brokerage services for “support for planning personal budgets”. Instead personal budget users tend to look for free support brokerage from professionals they already know, rather than pay for professional support brokerage. The above points notwithstanding, many service users need extensive support in order to access personalised budget schemes, to manage money, budgeting and accounting, to access the required services, and to employ and manage staff.

The amount and type of support, and who provides it, varies between countries and programmes.

Based on the HRB Review and other available reviews, it appears that a package of services is typically provided by the funder or organisations on contract to the funder at no cost to the personalised budget recipient. These supports include assessment and review of needs, person centred planning and review (including risk assessment and safeguarding), guidance on use of personalised budget monies, guidance and possibly training on employers’ obligations.

Typically, personalised budget recipients can opt to contract with an agency or agencies to fully manage the budget on behalf of the personalised budget recipient, manage the payroll of support workers employed by the personalised budget recipient, and employ or contract directly all support workers or caregivers who support the personalised budget recipient.

2.3.2 Organisation of brokerage and other support services

A review of 11 jurisdictions found that, “the amount and type of support, and who provides it, varies between countries and programmes, but it is frequently referred to as ‘brokerage’. It usually involves the provision of information and advice, but may also offer practical help in relation to tasks such as recruiting personal assistants, drawing up contracts of employment, operating a payroll, and so on”⁷. A study from Canada found that direct payment⁸ and host agency⁹ were the most economical, but microboards¹⁰ offered a lot in the form of improved network support and building social capital. A review in New Zealand of host agencies suggested that the human resource support/advice

⁷ Gadsby. E., (2013) Personal Budgets and Health, p.33

⁸ “Direct funding” is defined by Stainton et al as a payment which “allows the individual, family or their representative(s) to receive funding directly to retain and manage agreed supports”

⁹ “Host agency funding” is defined by Stainton et al as funding “channelled through an agency selected by the individual or family. The agency then supports the individual and/or their family or representative to utilise and manage their funds for agreed supports”

¹⁰ The microboard, is defined by Stainton et al as “an incorporated entity, [which] is a small (micro) group of committed family and friends (a minimum of five people) who join together with the individual to create a non-profit society to receive and manage the funding. In this structure, the individual requiring support, and their network, are the members of the board, and the board’s only purpose is to support the single individual”.

and payroll functions carried out by host providers might be provided more efficiently by aggregated host entities operating at national or regional rather than local level.

2.3.3 Regulating brokerage services

There was no evidence found amongst the literature reviewed regarding if and how brokerage services are regulated in other jurisdictions. Some reviews have highlighted concerns that the cost of brokerage was reducing people's budget for care and support. Many English local authorities provide brokerage in-house (by separating assessment and planning functions). One study in the Netherlands found that, "the unchecked proliferation of independent support agencies, and lack of financial oversight, proved problematic when unscrupulous broker agencies employed aggressive marketing tactics, and in some cases stole parts of the budget". One study highlighted concerns in the United Kingdom about conflicts of interest where some organisations are both providing services and brokerage.

2.4 Governance and accountability

2.4.1 Options for allocation or payment of funding

The literature review identified three main ways that a user can access a personal budget:

1. a direct payment to their bank account
2. a payment to an account held by the statutory funding body or a third party who 'manages' it on their behalf, or
3. a mix of the two.

A distinction was also made between two models for paying a personalised budget; an open model and a budgeted or planned model. The 'open model' is where cash payments are allocated with few limits on supports, few strings attached and limited accounting requirements. In practice, the majority of the cash allowances go to pay informal caregivers in 'open models'. The 'budgeted or planned model', "maintains a more direct connection between a participant's needs and the goods and services purchased to meet those needs". There are more restrictions placed on how the money can be spent (although these vary widely), and they are audited more carefully. The 'budgeted or planned model' is much more common than 'open model' programmes.

2.4.2 Accountability

Table 2 below summarises the financial reporting requirements in each jurisdiction. All the jurisdictions except Austria require financial reporting on expenditure. The Austrian example was a payment to carers which didn't require a support plan, so perhaps it is not comparable to some of the other schemes.

Table 5: Personalised Budgets in selected jurisdictions according to financial reporting requirements

Country	Budget deployment	Financial reporting
England	Notional budgets, budgets delegated to third parties, or direct payments.	Detailed financial accounting.
Belgium	Notional budgets (budgets with a drawing right) or direct payments. The choice is not always that of the individual.	Budget holders have to account for all expenditures
France	Direct payment, or paid directly to the service provider.	Use of budgets strictly controlled and users must justify expenditure.
Germany	Direct payment or notional budget.	Accounting always necessary but varies according to locality. Some areas have very strict procedures; others less so.
Netherlands	Direct payment with options to outsource some aspects (e.g. salary administration), delegate in full to 3rd party organisation, or to establish a foundation (e.g. pooling budgets to collectively engage assistants) ¹¹ .	Budget holders must submit periodic costings of how they spent (all but a tiny percentage of) the money. Costly budget holders are assigned to use a fiscal agent.
Austria	Direct payment. Where individual is cognitively impaired, someone is appointed to manage the budget.	None
US	Cash and counselling pilot used flexible vouchers. Some states provide cash directly, others use fiscal intermediary to handle payments.	Budget holders must account for almost all their expenditure.
Canada	No direct payments. Funds managed by an agency.	Individuals submit 'purchase of service' reports, along with invoices, bi-weekly or monthly.
Australia	No direct payments. Provider always holds the budget.	Limited responsibilities for individuals.
Finland	Service vouchers, given directly to the individual.	No information available.
Sweden	Direct payment, unless beneficiary specifically requests that it be paid to the chosen service provider.	Budget holder sends simple monthly report of the hours of work carried out by the assistants

¹¹ This information does not reflect the changes introduced in the Netherlands since 2015.

2.4.3 Training for personalised budget holders around responsibilities as employers

Typically, either the funder directly or by way of its contract with a host or brokerage service provides some employer supports to personalised budget holders who wish to become employers. Scotland has produced statutory guidance which outlines how local authorities should develop effective arrangements to ensure that all prospective employers are aware of, and discharge, their responsibilities in relation to safe and effective recruitment. In New Zealand host agencies provide support and guidance on employers' obligations to personalised budget holders. In the USA Cash and Counselling programme, all service users were required to undergo training on how to set up a support plan and how to recruit and train workers.

2.4.4 Quality assurance

One literature review noted that there is, "no international evidence to suggest that there are any particular risks posed where personalised budgets are used to purchase health care. However, this is indicative of the lack of research in this area, rather than a lack of risk". A number of reviews have highlighted risks associated with personal budgets rather than any hard evidence of poorer standards of care funded with personalised budgets. These risks include:-

- the expansion of low-quality employment, which has made it very difficult to control the level of quality of both employment and care
- the creation in some jurisdictions of unregulated, 'grey' markets which fall outside of employment law
- the availability and employment conditions of personal assistants. This can result in problems with recruitment, given competition from other providers, and insufficient applicants with appropriate qualifications/qualities

Research found that personal assistants employed by personalised budget holders regard themselves as able to provide a much higher quality of care than is possible when employed by a care organisation, and that service users are more satisfied with their support than with traditional personal assistance programmes

In England, a number of local authorities are considering the introduction of a register of personal assistants but notes that such a register would impact on the trade-off between ensuring those providing support have a certain level of skill and support and flexibility for personalised budget holders to hire whomever they wish to provide them with support.

2.4.5 Adult safeguarding

Literature highlights the need for personalised budget arrangements to be aligned with safeguarding considerations. Personalised budgets are seen to shift responsibility for care from the service provider to the users themselves which could put service users at risk of abuse and neglect, in particular, if the user purchased unregulated services. The need for a "cultural shift towards positive risk-

taking and risk enablement which should be an integral part of the self-directed support process”¹² is highlighted in some of the literature.

There is very little discussion in the literature about how risks of “abuse or neglect” are managed in the context of personalised budgets.

Risk, the literature states, can be managed in multiple ways. For example, by:

- firming up adult safeguarding policies
- conducting regular expenditure reviews
- building risk assessment into the support plan
- providing better guidance for care coordinators
- providing better information for personal budget holders
- providing training for staff, users, carers and family members, and;
- conducting regular (appropriate) audits

One study highlights that it is important that someone (usually the social worker in other jurisdictions) remains responsible for risk monitoring and risk assessment once the support plan and personal budget are in place. While the role is likely to fall to the HSE in an Irish context, the Task Force has not provided a recommendation as this is largely an operational matter for the HSE.

2.4.5.1 *Where breakdown of support arrangements occurs*

There is little evidence of who is responsible and has a duty of care when personalised budget arrangements breakdown. However, in the UK at least it appears that the local authority [i.e. the funder] does have a duty of care if a direct payment recipient’s care / support arrangements break down.

2.5 Financial Sustainability

As personalised budgets have only recently been introduced or have been significantly revised in many countries, there is little evidence available with regard to the financial sustainability of these systems. Furthermore, the different models and disability support systems operating in each jurisdiction make comparison difficult. However, the experience of personalised budgets in several countries has identified some risks to service users as well as some financial risk to service providers and funding sustainability risks at a state level.

Individualised budgets were found to be cost-effective overall, but with a great variation between people with physical disability, intellectual disability, a mental health difficulty and older people. There is mixed evidence on whether the introduction of personalised budgets results in cost-savings and/or whether any system can be introduced in a cost-neutral manner (without impacting on the original policy objectives of autonomy and choice). Some countries found that costs were higher than they had expected in the early years after introduction, mostly due to unmet need in the exist-

¹² SQW (2017) Research into the implementation of resource allocation models. NDA unpublished

ing system. People with unmet need in the existing system may drive costs upwards in the early years of a personalised budget system

The HRB evidence review noted that transaction costs such as implementation costs, costs of commissioning or arranging services were almost always underestimated in plans for introducing personalised budgets. The extent of this underestimation was not available in the published literature.

At the state level, problems have arisen where broad eligibility criteria were set and where a high level of previously unmet need required additional funding. The international evidence on personalised budgets cautions against open-ended **eligibility** or **open-ended budgets**. Where eligibility criteria are narrowed and controlled, this limits either the number of service users that can avail of a personalised budget or it limits the range of services available or limits the expenditure. The limited number of cost-effective studies of the personalised budget approach versus more traditional approaches found personalised budgets to be cost-effective, although there were some caveats in the findings. A very liberal approach to eligibility can lead to increasing expectations and new demand (e.g. The Netherlands). When budget cuts are necessary it can mean that either eligibility criteria remain the same but the levels of support changed or eligibility criteria are narrowed thus limiting the number of people that can avail of the service.

2.5.1 Risks identified in the literature that may affect financial sustainability

Industrial relations issues relating to staff terms and conditions of employment are a potential challenge. There may be a fear that where the person chooses their own staff, the role of the staff member may diminish and their responsibilities reduce. It may be difficult to recruit personal assistants and other, costlier, options may have to be used. There is also the risk that a 'two-tier' workforce may emerge with unregulated and unprotected personal assistants who are cheaper being hired in place of more expensive regulated and protected workers.

There may be a financial risk of double running costs during the transition phase (that is, running the old and new systems in parallel). Competition between private suppliers may result in cherry picking, leaving the state to provide the uneconomic services.

People may use their individualised budget to pay for things they may have previously paid for 'out-of-pocket'. Funding may replace family care that is already being delivered free of charge.

The literature suggests that levels of fraud in other jurisdictions were low and that underspending was more common than overspending or abuse. Evidence suggests that high levels of regulation did not assist in reducing fraud, but that it can lead to a substantial administrative burden.

Research shows that fraud can be reduced during the assessment phase (where service users or service providers could 'play the system' to gain more resources) through the development of clear criteria and providing good training to the assessors. It can also be prevented through the use of online systems of payment which provide a ready audit trail.

In cases where service users are deemed higher risk, then tighter controls can be put around their budget, for example, switching from monthly to weekly payments to limit their scope to over-spend.

2.6 Existing Irish models of individualised funding

2.6.1 National survey on the prevalence of personal budgets

The National Disability Authority was asked to gather baseline data on the prevalence of personalised budgets in Ireland. 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 amounting to 290 individuals in total. Some responses were incomplete, so the analysis below refers to 11 organisations and 283 individuals using some form of individualised funding. Due to this small sample size, we are limited in the conclusions that we can draw from this research.

From the survey results, it was possible to obtain a breakdown of the purpose for which the personal budget was used. The personalised 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.

The survey also examined why a personalised 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%).

It should be noted that some of the funding types covered by the survey could be considered as individualised funding arrangements rather than personal budgets. This points to varying definitions of what exactly a personalised budget is, from a direct payment to individualised funding.

2.6.2 Task Force learning from Irish experience

Personalised budgets / individualised funding arrangements have been established for a small number of people in Ireland through pilot projects. At its third meeting, the Strategy Group met with representatives from a number of these: Possibilities Plus, Áiseanna Tacaíochta, National Learning Network, the Bridging the Gap project and Muiriosa. These organisations presented the key findings from their work on personalised budgets. All reported significant improvements in the lives of their participants with service users experiencing positive changes such as a growth in self-confidence, self-esteem, exercising more choice and control and a greater sense of personal development.

The particular benefits and challenges experienced by the participants were considered by the Task Force and have informed the recommendations subsequently agreed. Some of the challenges identified included accessing funding, limitations in family and natural support networks, high levels of bureaucracy, difficulties in meeting regulatory requirements and challenges in achieving a shift in attitudes and mindset in those working in the service sector. As would be expected, it was found that personalised budgets were not suitable for everyone and that the pace of entering a personalised budget agreement varied very much from person to person.

Both the Strategy Group and the Advisory and Consultative Group included people with ongoing experience of personalised budgets in Ireland. Their input contributed significantly to the Task Force deliberations and supported the informed development of recommendations.

2.7 Conclusions

The international evidence review and input from experience of personalised budgets at national level was critical in informing the Task Force of the range and scope of various models of personalised budgets from around the world. While it was clear that there was no single system that was replicable in an Irish context, a number of the key elements were transferable and have been incorporated into the recommendations proposed by the Task Force.

One of the key findings is that a personalised budget should be spent for the direct benefit of the person with the disability and not their care provider, support worker, or a family member. The research suggests that change should be introduced over a fairly long period of time using a strategic and phased approach.

Transitional funding was used in other jurisdictions and is needed to develop new systems, train staff and fund the piloting and trials of new processes. The Task Force noted the need for investment in a pilot of a new system to highlight gaps in the system, test funding assumptions and implications, and assist in managing and addressing any challenges that arise.

3 Supports for individuals and families availing of personalised budgets

3.1 Advice Paper on supports to apply for and use personalised budgets

The Advisory and Consultative Group was asked to provide their views on the supports to apply for and use personalised budgets. This work was completed at an early stage of the process and helped to inform much of the proposed structure and administration of personalised budgets, as well as the final recommendations of the Task Force.

The focus of this Chapter is on the supports that an individual would need; it does not delve too deeply into the process that would sit behind these supports. These processes are considered in more detail in Chapters 6 and 7.

3.2 Task assigned to the Consultative and Advisory Group

The task of identifying the **supports to apply for and administer personalised budgets** required consideration of the following requirements:

- information infrastructure
- brokerage system, back-office services, any other support services
- support to prepare applications
- support to develop and implement individual support plans, develop circles of support
- role of personal advocates
- supports for individual administration, accounting, payroll, timesheets etc.
- supports for human resource issues as they may arise
- model templates for micro boards and circles of support
- support for assistance with financial decision making.

And, also consideration of issues relating to employment of support workers, including:

- requirements for education on the responsibilities of individuals and families if they become employers
- mechanisms to assist individual and families in discharging these responsibilities
- alternatives for individuals/families who do not wish to become employers
- implications for support workers.

It should be noted that the Advisory Group undertook its task in advance of, and feeding in to, the proposals for a model and process for personalised budgets that would emerge from the other work streams in the Task Force work plan.

The Advisory Group emphasised in their work that people with disabilities interested in using a personalised budget will need to be supported at a number of stages in the personalised budget process. Some elements of support may need to be very different for people depending on their disabilities and circumstances. The following summarises the Advisory Group's views on the range of supports required to access and administer personalised budgets at each of the relevant stages.

3.3 Recommended supports identified by the Task Force

3.3.1 Education, Capacity Building and Training

Some individuals, and where appropriate their families, will need support to build their capacity to develop a plan based on developing valued social roles. Therefore, education and capacity building will be required for some people in addition to training on the practical elements of managing a personalised budget.

3.3.2 Information supports

Formal information should be provided by an independent body (possibly as a one-stop-shop model), including information on processes, finances, and options and related legal duties e.g. employer role for those who choose to directly employ their support workers. Much of this information and further detail on supports for employers is available from the Citizen's Information Board.¹³

Information is also needed on what tasks, if any, the person with a disability, or their family where appropriate, would have to take on to do themselves if they opt for a personalised budget.

Organisations could be funded to provide information, education, advice and guidance on personalised budgets. Some people may need support throughout the application and assessment process from a peer via a peer-to-peer support network.

Training on personalised budgets would need to extend beyond the individual to include training for relevant health social and care staff so that they can provide information on personalised budgets and promote and facilitate them.

3.3.3 Application process

The application process should be universally designed so that it is easy to understand and engage with. It should allow people with a disability to quickly and easily get an answer as to whether they are eligible for a personalised budget or not.

Staff involved with the application process should keep the person with a disability informed about how their application is progressing. The application process should be designed in a way to ensure that those applying for personalised budgets are not required to repeatedly give their personal information to a variety of professionals / administrators involved in their assessment / application for a personalised budget.

3.3.4 Assessment

Some people may need information and support during the assessment phase. Also, it is important that the assessment phase identifies the supports the person with a disability would require to administer a personalised budget.

3.3.5 Planning

¹³http://www.citizensinformation.ie/en/employment/employment_rights_and_conditions/employment_rights_and_duties/employer_obligations.html

The level of planning required will be different for different people, so supports for planning would need to reflect these different circumstances. Some planning pathways suggested by the Advisory Group may involve:

- A short process to develop a support plan for some may involve only guidance and advice
- A “Discovery” type planning process for others entailing support for individuals and where appropriate their family and support network, to identify and plan life goals e.g. a facilitator.
- A Circle of Support may be involved in planning for some people and not others. In some cases this may entail a facilitator to support development of circle and to support in planning process etc.

3.3.6 Supports to Administer Personalised Budgets

Basic guidance and training will need to be provided to all who require it but also some people may require additional assistance. Brokers could be used by people who require assistance with any or all of the following; coordination of supports; assistance with reporting and accounting matters; payroll supports; and staff employer supports.

3.3.7 Supports for those who want to employ their own staff

Support from a relevant body e.g. brokerage or other body, for the individual who wishes to hire their own staff might include; identifying what they want from a support worker ; identifying what characteristics might be important to them in a support worker (similar interests, similar outlook, etc.); assisting them to develop an advertisement; support for interview and selection processes; drafting a contract; vetting; and payroll.

Guidance will need to be developed on some legal issues, which may impact on personalised budgets (such as employment disputes, terminating employment contracts, transfer of undertakings etc).

3.3.8 Review

The person with a disability and the funder will need to review at appropriate intervals the levels of support needs, the plan goals, and adequacy of support arrangements in place. A number of people with disabilities may need some support around communicating their views during the review phase.

These and other supports to make the personalised budget process as easy to use as possible (e.g. accessible process, on line process etc) are discussed in more detail below.

The learning from other people using personalised budgets should be gathered, as the experiences of others can be helpful to those thinking about using personalised budgets.

3.4 Conclusions and Recommendations

3.4.1 Conclusions

The Advisory Group’s report on the supports required for a personalised budget was a key input to the subsequent work done on the administration process proposed and informed several of the recommendations of the Task Force.

The Advisory Group emphasised in their work that people with disabilities interested in using a personalised budget will need to be supported at a number of stages in the personalised budget process. As a result, the Task Force has recommended that comprehensive guidance is developed to support people through the process of considering and applying for a personalised budget. It also recommended that a standardised assessment tool be put in place.

A number of the recommendations reflect that there is a need for a significant amount of preparatory work to ensure that the person is aware of both the risks and responsibilities of using a personalised budget. They also reflect that training will need to be undertaken across the system, including by service providers and support staff.

The key recommendation from the Task Force is the need for initial demonstration projects, which will assist in providing some of the shared experience and learning required to further extend and promote the use of personalised budgets. The development of many of the supports identified by the Advisory group can be commenced and tested during the initial demonstration projects.

3.4.2 Recommendations related to this Chapter

- Funding should be approved on the basis of a standardised assessment of individual need. A profiling tool should be selected for use in the initial demonstration projects. (*Recommendation 6*)
- Learning from the demonstration sites should inform the development of guidelines required to enable further implementation of a personalised budgets system. This should include specific provisions to support the introduction of a direct payment model of personalised budgets and graded levels of accountability. (*Recommendation 15*)

4 Personalised Budgets Consultation Process – Summary of Key Findings

4.1 Consultation Process

The Task Force identified a need to carry out consultation with civil society at relevant intervals, including with the individuals in the Reference Group and through other fora, on emerging options for administering a system of personalised budgets.

This was done with the aim of ensuring that the person with a disability was at the heart of all decision-making. Their views were incorporated by collating key themes and points emerging from the consultation and feeding these back to the Strategy Group and the Advisory & Consultative Group.

A consultation document was produced including a set of consultation questions and a questionnaire. An Easy to Read version of this questionnaire was produced to facilitate the participation of persons with additional support needs.

Four regional consultation meetings were held in Cavan, Cork, Dublin and Galway. These were held during October 2017. The consultation meetings were targeted at the members of the Task Force Reference Group. A number of representative groups including Inclusion Ireland, the Centres for Independent Living, LEAP, the Disability Federation of Ireland (DFI), the National Federation of Voluntary Bodies and the Not for Profit Business Association (NFPBA) were also asked to nominate members to attend at each meeting, to ensure that a range of views were represented. At each meeting, participants were divided into small facilitated groups. A note taker was assigned to each group. Views, opinions and feedback were recorded.

In total 130 individuals participated in the regional meetings, which were facilitated by personnel from the Department of Health, the HSE and the NDA.

A call for public consultation was published on the Department of Health's website which facilitated organisations and individuals to submit their views in writing on how Personalised Budgets could operate in an Irish context. This was promoted through advertisements in national newspapers and disseminated through representative groups. The questionnaire consisted of 9 open-ended questions about the respondents' views on Personalised Budgets. The consultation process ran throughout the month of October.

Over 200 individuals and organisations gave their views during the consultation period. Some individuals and organisations participated in the regional meetings and also completed the questionnaire.

A summary of the responses to the consultations is available on the Department website:
<http://health.gov.ie/disabilities/task-force-on-personalised-budgets/>

4.2 Conclusions and Recommendations

4.2.1 Conclusions

The consultation process provided valuable insight to the Task Force of to the lived experience and real life expectations of people who hope to avail of a personalised budget. Other people whose voices were heard were family members, advocates for people with disabilities and service providers. The Task Force particularly wishes to thanks the Reference Group for their input into the consultation process.

Many of the key themes that emerged over the course of the consultation process strongly echoed those of the Advisory Group report outlined in Chapter 3. The recurring theme across all consultations was that people with disabilities want greater choice and control in how they engage with supports and services.

At the regional events in particular, the view was expressed that everyone has different support needs. Personalised budgets should therefore be flexible and take account of these differences. The need for good information and guidance before a person takes up a personalised budget also featured heavily, with calls for training and information campaigns.

There was agreement at the consultation events that there is an understanding that the development and implementation of a system of personalised budgets was a complex task that would evolve over time.

The idea that any oversight of personalised budgets should be proportionate featured heavily, and was a concept picked up by the Task Force and applied to the recommended administrative process.

4.2.2 Recommendations related to this Chapter

- A standardised training package should be made available on the various elements of managing a personal budget. Training should include a focus on HR law, finance, employment relations etc. (*Recommendation 9*)

5 Vision and Values

The Task Force recognised that an operational vision and set of guiding values should underpin the introduction of a system of personalised budgets. Drawing on the international evidence reviews, the experience of service users in Ireland and the views and expectations expressed through the consultation process, the Task Force proposes that the following vision statement and set of principles should apply to personalised budgets. The vision statement was agreed at a plenary session of the Strategy Group and the Advisory and Consultative Group, and represents the collective view of both.

5.1 Vision Statement

Personalised budgets will enable a person with disabilities to have choice and control over individualised supports in all aspects of their lives, to enjoy an independent life and to be an active participant in their community.

5.2 Guiding Principles and Values underpinning the Personalised Budgets Process

Translating a set of principles into operational practice may be challenging in any new system. It is recommended therefore, as a means of embedding these principles, that an individual's personalised budget be designed in accordance with an outcomes framework developed by the NDA and described below.

The Task Force felt that the following principles were key considerations for a person with a disability:

Choice	I can make choices and decisions about my life and my support plan
Dignity	My privacy and dignity is respected and I am given the chance to try new things and take risks
Empowerment	I am supported to have my say and take control of my life
Equality	I have rights like others and I get the information and support I need to understand and realise my rights
Independence	I am supported to be as independent as I can be
Person centeredness	I am an individual with my own life experience, gifts, skills and culture. My person-centred plan supports me as a person of value to be part of my community
Respect	I am treated as an adult and my views are respected

In keeping with the values that a personalised budget should embody as set out above, there are also a number of principles that should underpin the way in which a personalised budget system is implemented or operated.

Creative	All people involved in the Personalised Budget Process should be supported and encouraged to think differently; to be creative about how resources can be used to best effect that suits each person.
Flexible and proportionate	A Personalised Budgets system should not be one size fits all. A Personalised Budget should work flexibly and proportionately in a way that reflects each person's need and circumstances.
For the benefit of the person with a disability	A Personalised Budget should be spent for the direct benefit of the person with the disability and not their care provider, support worker, or a family member.
Impartial	The process for allocating a Personalised Budget and the rules surrounding how it can be used, will be fair, rational and transparent
Equitable	A Personalised Budget should not advantage or disadvantage a person who chooses to use one.
Informative	Information about what to expect from the Personalised Budget process should be clear and well communicated.
Non duplication	HSE should not fund through a Personalised Budget anything that is the responsibility of another Government Department or Statutory Agency
Efficient	The Personalised Budget should be spent in the most efficient way possible, with every effort made to ensure the supports or services purchased are cost-effective.
Outcome focussed	The Personalised Budget should be built around the Transforming Lives nine high-level outcomes framework; making sure that the services and supports are arranged to provide the best chance for the person of achieving them as relevant and appropriate to their individual circumstances and goals.
Portable	A Personalised Budget should enable the supports and services follow the person, rather than prescribing where support should be delivered.
Universal	The Personalised Budget should be an option open to all adults with a disability requiring a disability support currently funded by HSE Disability Services.

5.3 Outcomes

A focus on outcomes is considered to be an essential part of the recommended service delivery framework under Transforming Lives. The National Disability Authority developed a framework for outcomes measurement for the proposed model of person-centred services. This framework was approved by the Steering Group for Transforming Lives. It is acknowledged that achieving these outcomes fully is beyond the scope of HSE funded disability services alone, but can be a useful reference point to enable individuals identify supports and set goals that lead to positive outcomes.

Table 3: Disability Services Outcomes Framework

	Outcome	Sub-domains
	Disability service users:	
1	Are living in their own home in the community	Ordinary housing Suitable housing (e.g. adapted) Choice of who the person lives with The run of your home Privacy
2	Are exercising choice and control in their everyday lives	Choice Control Everyday routines Major life decisions Positive risk-taking
3	Are participating in social and civic life	Social life Socially connected/not lonely Community activities Civic activities Can access the community (accessibility/transport/mobility) Attends church if so wishes
4	Have meaningful personal relationships	Family Friends Intimate relationships
5	Have opportunities for personal development and fulfilment of aspirations	Education Training Education/training outcomes Realisation of personal goals, both long-term and short-term
6	Have a job or other valued social roles	Employment Other valued social roles Doing things for others
7	Are enjoying a good quality of life and well-being	Satisfaction with life
8	Are achieving best possible health	Physical health Mental health Healthy lifestyle Preventive care
9	Are safe, secure and free from abuse	Safety Security and continuity Being respected, listened to Freedom from abuse

5.4 Conclusions

The Task Force concluded that the key purpose of introducing personalised budgets is to provide more choice and control for people with disabilities in selecting their supports and services.

Following extensive discussion on eligibility, it was agreed that a personalised budget option should be open to all adults with a disability who are receiving HSE-funded Disability Services.

It is the view of the Task Force that expenditure under a personalised budget should be linked to the achievement of outcomes as specified within the agreed outcomes framework for the disability sector. The focus of a person-centred plan should be on supporting the person towards achieving any or all of the nine outcomes under the outcomes framework.

6 What the personalised budgets administrative process will look like

6.1 Introduction

Early in the process, the Task Force accepted that there was no single approach to implementing a system of personalised budgets that could be adopted from another jurisdiction. Research indicated that further technical work would be required to support the work of the Group. The design of a system, appropriate in an Irish context was assigned to a dedicated work stream in the Task Force work plan.

The Department issued a request for tender to develop potential administrative and governance frameworks for implementing personalised budgets in an Irish context, to form the basis for input to the Task Force's final report and recommendations to the Minister. Following a competitive tendering process a consultancy firm were appointed by the Department of Health in July 2017. The consultant's full report is available on the Department website: <http://health.gov.ie/disabilities/task-force-on-personalised-budgets/>

The Task Force took into consideration the consultant's report and it formed the basis of a number of recommendations. One of the main points in the consultancy report was that, in line with the types of personalised budget commonly offered internationally, the Task Force should adopt (consider?) three payment options: (i) Person Managed Fund, (ii) Co-managed with Service Provider and (iii) Broker Managed. A fourth funding arrangement, where someone chooses a mix of options 1, 2 and 3 may also be possible in the future. The Task Force also requested that in designing a system of personalised budgets, the consultants should set out a range of governance options at appropriate stages and these are described in the next chapter¹⁴. The consultants reported to the Task Force in November 2017.

Based on this research and appraisal, the Task Force sets out a set of proposals for personalised budgets for people with a disability. The final implementation of the model is dependent on outcomes from the demonstration projects.

Note that the "person" referred to throughout this process represents the person with a disability and/or his/her support network e.g. advocate or chosen representative. In certain circumstances a family member, advocate, guardian, decision-making assistant, co-decision-maker or decision-making representative may be nominated to act as fund manager and would assume the associated reporting and accountability responsibilities.

6.2 Types of supports and services that can be funded

¹⁴ Good governance as defined by the HSE Quality Assurance and Verification Division, sets standards of accountability, transparency, responsiveness, equity, empowerment and inclusiveness. [HSE Quality Assurance & Verification Division](#)

People with disabilities who are eligible for HSE-funded disability supports and services will be able to apply for personalised budgets. However, it should be noted that not all services and supports currently provided by the HSE will be funded by a personalised budget in the early stages of the programme.

The following list outlines some of the main supports that people will be able to purchase using a personalised budget, although the supports that are available at a particular point in time may be limited in cases where there is a lack of availability of or funding for a particular support:

- Support for engagement in community based activities
- Support for engagement in social activities
- Employ someone to help with the activities of daily living
- Employ someone to provide support for household management, e.g. cleaning, cooking
- Personal support to attend training funded by the HSE (e.g. rehabilitative training)
- Centre-based day services.

A more detailed list of the supports and services funded by HSE Disability Services is available at www.health.gov.ie.

It should be noted that several supports that are provided by the HSE are not funded by HSE Disability Services, and are therefore not under the remit of the Task Force to make recommendations on. These include adult therapy services and aids and appliances.

Given the high proportion of the overall HSE Disability Services budget that is spent on pay costs (82-85%), it could reasonably be expected that a similarly high proportion of a personalised budget is likely to be spent on staff costs.

Day-to-day living costs (same type of expenses that a person without a disability is reasonably expected to meet, e.g. bills, food and drink, mortgage or rent, insurance) are not covered by a personalised budget in any jurisdiction and therefore it is recommended that they not be funded under the Irish system. It should be noted that any use of a personalised budget should primarily be on the supports to engage in activities that will in turn help to achieve specified outcomes, but will not be used to meet the costs of an activity itself. For example, a person may pay for the support required to get them to an activity in the community, like a music or sporting event, from their personalised budget. However, the cost of the ticket for the event would not be covered by the personalised budget and the person would need to pay for this from their own funds.

6.3 Personalised Budget System Stages

6.3.1 Entry to a personalised budget system

An overview map of the proposed structure for entry to a personalised budget system is shown in Figure 2. This shows how a person may enter services in the future and following an assessment of support needs and approval of an indicative budget may then decide to go for a personalised budget, traditionally funded services or a mix of both.

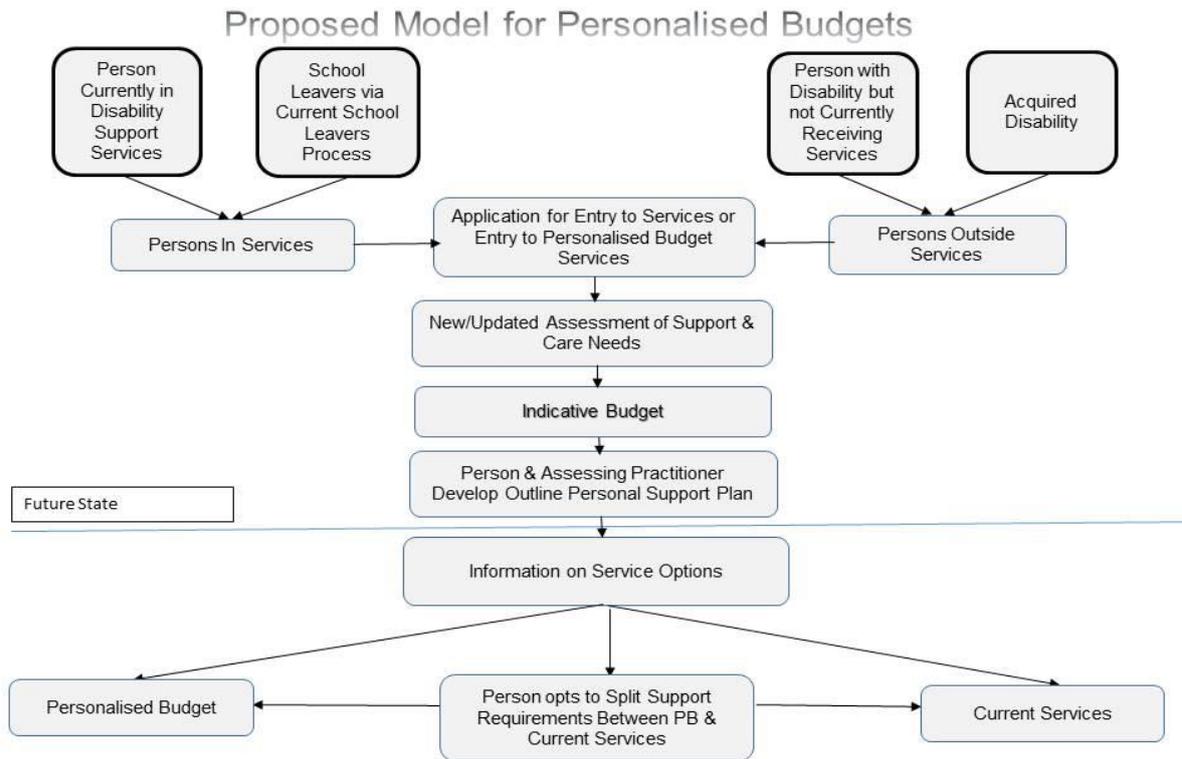


Figure 2: Proposed model for entry to Personalised Budget system

It is envisaged that an assessment of support needs will be carried out by an assessing practitioner¹⁵ using an agreed standardised assessment tool. This is vital to ensure that there is equity, consistency and good governance of personalised budgets. The HSE is in the process of deciding on a standardised assessment tool to be implemented across all Disability Services. While national implementation may take some time, it is hoped that a standardised assessment tool will be available for the roll out of the demonstration projects. Following assessment an individual support plan will be drafted and reviewed periodically based on desired outcomes described in Chapter 5.

Stages in the application process:

6.3.2 Stage 1 – Information on Supports Options

¹⁵ The main role of the Assessing Practitioner is envisaged as assessing support needs in collaboration with the person, and giving information and guidance to the person to enable them to make an informed decision on whether a personal budget is suitable for them and if so which is the right option/ model for them.

The consultants did not make any recommendations as to who the assessing practitioner should be, as this is an operational matter outside their scope. It was noted that it is important that the person be placed at the centre of this process and communication will take the form of a two-way conversation that places the assessing practitioner in a support role.

People should be provided with relevant information to determine if a personalised budget may be a desirable way to meet their support needs. This process may take a number of forms e.g. an online application system, telephone support line or face to face meetings. Comprehensive information options should be provided at this stage, in all accessible communications formats including Plain English and Easy To Read versions, to ensure that people may determine if personalised budget is a suitable option for them. This may also include peer-to-peer support to ensure that both the benefits and barriers to a personalised budget are fully understood. The outcome from this process will be the person deciding to proceed with an application for a personalised budget or to remain in current services. The person will be able to review that decision at any time.

6.3.3 Stage 2- Application

People interested in a personalised budget may apply using a written application form that would be reviewed by an 'assessing practitioner'. They may also apply by engaging in an assessment together with the assessing practitioner where support needs are discussed and agreed together. This is suited to individuals who may require additional support through the application process and beyond.

The application stage will result in the person either availing of a personalised budget, remaining with current services or availing of a part personalised budget and part current services. In some cases, the support services requested may be currently unavailable through a personalised budget and the person may decide to remain in current services. An indicative budget will be agreed for those who choose a personalised budget.

The person should be given the option to discuss any decision made about their application with their practitioner and an appeals process should be put in place if a person is not satisfied with a decision taken. The appeals process is described in more detail at 6.3.7.

6.3.4 Stage 3 - Support and Planning

If the personalised budget is accepted, the person and assessing practitioner finalise and agree a personal support plan, including a spending plan, and discuss various payment options.

The process should be person-centred and provide applicants with a voice in the decision making process ensuring that personal support plans reflect the needs of the individual. An applicant should be supported in making choices regarding the services they wish to access. They should be supported to have a clear understanding of what the budget can be used for and what flexibility exists when choosing possible support options. The process should work towards the realisation of personal goals and fulfil the person's aspirations. As noted earlier the personal support plan will link to the outcomes described in Chapter 5.

6.3.5 Stage 4 - Implementation and Accountability

Once a decision has been agreed to provide a personalised budget the individual will discuss a suitable payment option with their assessing practitioner. In line with good governance, a contract will be signed by both parties outlining:

- i) the amount of funding to be issued
- ii) details specifying what types of support can be purchased (the “spending plan”) and how these align with the agreed outcomes

The contract will require the individual to be clear and agree about the policies and processes in place that need to be adhered to in relation to the payment of the funding and how it needs to be accounted for.

There will be three payment options that a person may choose from:

Payment Option 1 – Person Managed Fund

Under this payment option, funds are transferred periodically to a dedicated bank account under the direct control of the budget holder. The budget holder then arranges for payments to be made to service providers or staff, etc. in accordance with the agreed personal support plan and spending plan. The person will be fully responsible for managing the account, paying for services, keeping appropriate financial records and submitting these to the HSE at the agreed intervals. With this payment option, the budget holder is likely to be entering into a contract with a service provider or they may be becoming an employer directly. While the person may not need to pay a third party for overheads associated with a personalised budget, this payment option attracts particular legal and financial responsibilities, including an increased administrative workload and employee management responsibilities. Information and support modules on various aspects of employment / contract law will need to be undertaken. These are set out in more detail in Appendix 10.3.

Payment Option 2 – Co-managed with Service Provider

In the case where it is agreed that the funding will be paid directly to a service provider, the contract for services will be between the HSE and the service provider but with the person determining and agreeing the services and selecting the service provider with the HSE. This model may appeal to people who want a direct relationship with the service provider but not the responsibilities of being an employer and/or entering a contractual relationship with the service provider. The person will undergo mandatory training of appropriate HSE approved training modules, will receive a list of HSE approved service providers and will select a preferred service provider. Under this model, the approved service provider is likely to be an organisation who has a Service Agreement with the HSE. Terms and conditions, including a personal support plan with a spending plan, will be agreed by the person and the service provider with input from the HSE. Once the terms and conditions are finalised a contract will be issued and signed by the HSE, person and service provider.

While the person does not directly meet administrative costs themselves in this model, they will be indirectly paying for the administrative overheads incurred by the service provider (e.g. staff costs, back office and other operational costs). This is in keeping with the current service provider funding mechanism.

Payment Option 3 - Broker Managed Fund

The person will undergo training of appropriate HSE approved training modules. This will equip the person with the skillsets necessary to engage the appropriate services of a suitably qualified brokerage company.

The person will receive a list of HSE approved brokers and will review and engage in discussions with them to determine which of the following broker services best meets their needs:

- a) Broker as the employer
- b) Broker as facilitator
- c) Broker as financial intermediary /manager

The person will select their preferred broker and broker service and will agree the terms and conditions with them, including all charges associated with the cost of brokerage in a transparent and accessible format. The literature review indicates that the costs of the broker are usually met from within the personalised budget.

Option A) Broker as the Employer

The Broker will manage the whole process from helping to finalise the personal support plan and spending plan, sourcing suitable providers/employees, agreeing terms and conditions, appointing the providers/employees, monitoring the performance of the provider and reporting to the HSE. The broker will directly employ the service provider/employee and take on all responsibility for sick cover, holiday cover etc. The broker will be responsible for the reporting of financial information to the HSE and the person, in consultation with the broker, will report on the performance of the service provider/employee.

Option B) Broker as Facilitator

In this model, the Broker will support the person in finalising their personal support plan and spending plan, sourcing suitable providers, agreeing terms and conditions and appointing the service providers/employees.

The person may decide to use the broker as a once off service to facilitate and advise on setting up a personalised budget or they may keep on the broker as an advisor to help them with the running and monitoring of their budget.

Option C) Broker as Financial Intermediary / Manager

In this model, the person may decide to engage the broker to manage the finances on their behalf or to provide on-going management services.

The person would agree the specific role of the broker and agree a contract with them. The person/broker will report to the HSE on the financials and performance of the service providers or employees.

Person Managed Fund	Co-managed with Service Provider	Broker
		
Stage 1		
Information on Supports Options: Individual engages in an information and briefing stage		
Stage 2		
Application: Individual applies for a personalised budget through as-sessing practitioner		
Stage 3		
Support & Planning: Queries and payment options discussed		
Stage 4	Stage 4	Stage 4
<p>Implementation and Accountability Individual decides preferred payment model and finalises personal support plan, in consultation with Liaison Officer, Service Provider or Broker.</p>	<p>Implementation and Accountability Individual decides preferred payment model and finalises personal support plan, in consultation with Liaison Officer, Service Provider or Broker.</p>	<p>Implementation and Accountability Individual decides preferred payment model and finalises personal support plan, in consultation with Liaison Officer, Service Provider or Broker.</p>
<p>Person managed plan</p> <ol style="list-style-type: none"> 1. Payment made direct to Individual. 2. Individual pays for approved supports according to agreed support plan. 3. Individual becomes employer or enters into contract with service provider. 	<p>Co-Managed Plan</p> <ol style="list-style-type: none"> 1. Payment made by HSE to service provider selected by the person. 2. HSE pays for approved supports as agreed in support plan. 3. Contract between HSE and Service Provider. 	<p>Broker managed plan</p> <p><u>Broker as Employer</u></p> <ol style="list-style-type: none"> 1. Payment made to approved Broker 2. Broker pays for approved supports according to agreed support plan. 3. Broker as employer and enters into contract with service provider. <p><u>Broker as Facilitator</u></p> <ol style="list-style-type: none"> 1. Individual or approved Broker paid directly. 2. Broker supports individual to agree support plan and source support services. . 3. Broker or individual engage in contracts. <p><u>Broker as financial manager</u> Broker acts as financial manager and assists the individual to source services and agree plans with HSE.</p>
Stage 5	Stage 5	Stage 5
<p style="text-align: center;">Review</p> <p>Accounting, reporting mechanisms, and outcomes review agreed. Amendments to/withdrawal from personalised budget where required.</p>	<p style="text-align: center;">Review</p> <p>Accounting, reporting mechanisms, and outcomes review agreed. Amendments to/withdrawal from personalised budget where required.</p>	<p style="text-align: center;">Review</p> <p>Accounting, reporting mechanisms, and outcomes review agreed. Amendments to/withdrawal from personalised budget where required.</p>
Stage 6	Stage 6	Stage 6
Option to Appeal	Option to Appeal	Option to Appeal

6.3.6 Stage 5: Review

The review process is designed to ensure that the budget is being used in accordance with the personal support plan agreed at the outset. An **Accounting Review** is designed to ensure that the money is being spent in line with the support plan, that proper financial records are being kept and that further payments are approved until the next review. An **Outcomes Review** examines the broader operation of the personalised budget for the individual and its success at meeting the outcomes identified at the outset. Where appropriate the Outcomes Review may also facilitate adjustments to the assessment of support needs, personal support plan and level of budget assigned. These reviews are not intended to replace any ongoing support and interaction between the Liaison Officer¹⁶ and the budget holder but are intended instead to provide periodic reassurance that the personalised budget is appropriate and is operating as intended.

A clear reporting structure will be put in place and regular accounting reviews will be scheduled and carried out. This process should include the person monitoring and regularly reporting on the performance of the service provider and measures outcomes achieved against planned targets. These governance arrangements between the person, the service provider and the HSE will be agreed at the outset as part of the contractual arrangements.

The person will be responsible for the full management of the funds allocated and for paying the service provider or employee and keeping appropriate financial records.

6.3.7 Appeals and Complaints Processes

Where an application for a personalised budget is refused or the person is concerned with the allocated funding, a clear appeals process should be in place outlining what grounds an appeal can be made on, how to appeal a decision and how decisions are made in relation to applications and assessments. There should be a time line around this process.

The HSE Quality Assurance and Verification Division state that the purpose of the HSE Appeals Service is to provide internal, independent and impartial review of decisions taken by HSE personnel relating to applications by members of the public for specified service and entitlements where applicants are dissatisfied with the outcome of their application. This process should be applied to personalised budgets also.

Where a service user wishes to make a complaint about an aspect of the personalised budget system or its operation, rather than about a decision, a separate complaints process should be available.

6.4 Conclusions and Recommendations

6.4.1 Conclusions

¹⁶ The Liaison Officer will be involved in performance reviewing of the personalised budget with the person and in ensuring that the service providers, employees and/or broker delivers the supports to the Person to the expected quality standards and governance compliance requirements.

The consultant's report describes, in detail, the administrative and governance elements of a personalised system and includes a Strengths / Weaknesses / Threats / Opportunities analysis of the different options.

The report helped the Task Force to clarify the processes around application for and payment of a personalised budget. One of the key points is that for those not already in receipt of supports from the HSE, the person will need to go through an assessment of support needs (AOSN) before becoming eligible to apply for a personalised budget. For people currently in receipt of supports from the HSE, the person wishing to apply for a personalised budget will need to undergo a reassessment of their support needs, which the Task Force would see as occurring through a standardised assessment tool.

The proposed framework ensures that the level of oversight required for a personalised budget is proportionate to the amount of funding available to the person through the personalised budget.

The Task Force considered the contents of the report and based on the diversity of personalised budget systems internationally it recommends that the administrative process and the range of audit and governance arrangements described be tested in a series of initial demonstration sites. The outcome of these will then inform future roll-out of personalised budgets.

A copy of the full consultant report is available on the Department of Health website at <http://health.gov.ie/disabilities/task-force-on-personalised-budgets/>

6.4.2 Recommendations related to this Chapter

- A personalised budget may be used for support with daily living activities and participation in the community, including personal assistance or home care support. (*Recommendation 1*)
- A personalised budget should not duplicate any supports or services provided by another Department or Statutory agency or be used for day to day living costs such as rent, groceries, utility bills or other consumer spending. (*Recommendation 2*)
- The personalised budget arrangements will allow for three possible funding models:
 1. Self-managed fund
 2. Co-managed with HSE/Service Provider
 3. Broker/Intermediary managed. (*Recommendation 3*)
 1. The operation of personalised budgets will follow the five stages of: Information and Support
 2. Application
 3. Support and Planning
 4. Implementation and Accountability
 5. Review (*Recommendation 4*).

- Following agreement of indicative budgets a detailed spending plan will be agreed by the assessing practitioner and the applicant (and their family or other support network as appropriate), as to how their support needs will be met. (*Recommendation 7*)
- This support plan will take into account the supports that are provided through family, community or other state supports. The final personalised budget may vary from the indicative budget based on the outcome of this planning process. (*Recommendation 8*)

7 What the personalised budgets governance process will look like

7.1 Governance for personalised budgets

The consultants who advised on the administration process were also tasked with developing potential governance frameworks for implementing personalised budgets in an Irish context.

In designing a system of personalised budgets, the consultants were requested to set out a range of governance options at appropriate stages, taking account of the values and principles set out earlier. Good governance¹⁷, as defined by the HSE Quality Assurance and Verification Division, sets standards of accountability, transparency, responsiveness, equity, empowerment and inclusiveness.

Good governance requires clear rules and processes regarding the operation of personalised budgets and accountability for the spending incurred. From the perspective of the individual, good governance should include the following:

- Empowerment of the Person with a disability
- Person at the centre of decision making relating to their personal support plan
- Enhancement of quality of life for the Person
- Increasing the capacity of the Person to self-determine, shaping their own supports and services
- Importance of shaping the Person's own supports and services
- Mechanisms to ensure balance of need, risk and civil liberties
- Identified agreed outcomes.

At the outset, the person should be assisted and mentored in understanding the appropriateness or otherwise of using a personalised budget to meet their needs. The person should then be fully supported in making their own decisions in relation to areas of expenditure and it is essential that the person is at the heart of any process in relation to personalised budgets.

7.1.1 Levels of governance

As previously outlined, the reviews of international evidence found significant variation in the levels of oversight and governance applied in different jurisdictions. The consultants were asked to develop and apply three possible levels of governance which might be applied at various stages of a personalised budget system in Ireland. Their proposals are described as:

- **“Level 1”** which is a low or light-touch level, applying only minor restrictions or reporting / audit requirements. This provides a minimal amount of oversight by the system funder.
- **“Level 2”** is a moderate level of governance and requires increased frequency of reporting and review, imposing a higher level of oversight.

¹⁷ [HSE Quality Assurance & Verification Division](#)

- **“Level 3”** is a high level of governance with the most restrictions, significant oversight, review and reporting requirements.

When developing these, the consultants applied the concepts of proportionality and a ‘phased governance’ approach. These were applied to the three models to align with differing levels of support funding and to allow for reduced levels of governance once a personalised budget option, selected by the person, is in place and operating satisfactorily. It is important to note that governance and oversight applies not just to financial reporting or auditing but also to the monitoring of outcomes for the person in receipt of the personalised budget. Accordingly, varying levels of governance may be appropriate in specific circumstances.

The consultant’s report suggested that decisions around governance levels will need to be taken during Stage 4 “Implementation and Accountability” and Stage 5 “Review”. They identified seven specific topics on which different levels of governance will impact during these stages.

1. Process for approval of training courses
2. Role of Liaison Officer in the review of service providers by the person
3. Role of Liaison Officer in the selection of service providers by the person
4. Role of Liaison Officer in the review of brokers by the person
5. Process for selection of service providers under Payment Option 2 – Direct to service provider
6. Frequency of financial reporting and review
7. Frequency of outcomes review

7.1.2 Guidance and Information

If the person chooses to self-manage the funds, they may be entering into an employment contract with an employee or they may be entering a contractual agreement for services with a suitable service provider. They will need the skills to recruit and appoint employees and/or to invite and award contracts to service providers, to manage the funds, determine the outputs and outcomes required of the support services and the skills to comply with the governance reporting requirements of the HSE.

7.1.3 Role of Liaison Officers

Some level of support may be necessary in reviewing the range of service providers available to a budget holder and in selecting the preferred provider. The expectation is that the HSE will provide a list of approved service providers and this is reviewed by the budget holder, perhaps with the support of a liaison officer. Liaison officers may have a similar role in supporting a person to understand and select an appropriate brokerage service where they choose this payment option.

The person will be required to receive training in appropriate HSE approved training modules. This will equip the person with the skillsets necessary to select and engage the services of a suitably qualified brokerage company. The person will receive a list of HSE approved brokers and will review and

engage in discussions with them to determine which of the following broker service best meets their needs:

- a) Broker as the employer
- b) Broker as facilitator
- c) Broker as financial intermediary /manager

The Person will select their preferred broker and broker service and will agree the terms and conditions with them.

Different levels of governance may influence the role of liaison officers in these processes.

7.2 Selection of service providers or employees

The rules governing the appointment of service providers or employees will have to be determined. There will be rules regarding costs, qualifications, relationship to the person, and compliance with any relevant standards or regulations, etc. Terms and conditions will be finalised, and contracts developed. The service provider or employee will sign the contract with the budget holder. The service provider or employee will be registered or vetted in line with the National Vetting Bureau (Children and Vulnerable Persons) Act 2012 to 2016. The person will review the terms and conditions associated with the options they are considering and will choose their preferred service provider (or employee).

7.3 Review and monitoring

The personalised budget user will be responsible for the ongoing monitoring and reporting of financials and level of supports received. Where a family member, advocate, guardian, decision-making assistant, co-decision-maker or decision-making representative is nominated to act as fund manager, they will assume the associated reporting and accountability responsibilities for the fund on behalf of the person. A person may act jointly with a co-decision-maker as a fund manager or a decision-making-representative, with authority to make financial decisions. It is important to note that any person appointed as a fund manager, should act in accordance with the will and preference of the personal budget-holder.

This needs to be recognised in the governance structures of the personalised budget.

Table 7: Differences in Reporting Structures

Level 1 Governance (Low)	Level 2 Governance (Medium)	Level 3 Governance (High)
Reviews conducted by the budget holder and reported to the HSE.	Reviews conducted by the budget holder and reported to the HSE.	HSE will be involved in the reviews of service and performance.

The frequency of reporting depends on the Governance model applied. In developing these proposals, the consultants applied a 'phased governance' introduction to demonstrate initial effective-

ness of reporting and help mitigate risks at the start for the person and for the HSE. The concept of ‘proportionality’ was also applied in structuring the governance requirements for different levels of support funding. These reporting arrangements apply for all three payment options.

Table 8: Frequency of Accounting Reporting required

Level 1 Governance (Low)	Level 2 Governance (Medium)	Level 3 Governance (High)
<p><u>Funding of up to €20k</u> Initially once per month for two months. Once per year thereafter.</p>	<p><u>Funding up to €20k</u> Initially every six-weekly for three months. Every six months afterwards.</p>	<p><u>Funding up to €20 k</u> Initially once per month for two months. Every two months afterwards.</p>
<p><u>Funding of € 20-50k</u> Initially on a monthly basis for first three months and thereafter 2 times a year</p>	<p><u>Funding of € 20-50k</u> Initially on a monthly basis for first three months and thereafter 3 times a year</p>	<p><u>Funding of € 20 – 50k</u> Initially every two weeks for the first month and thereafter 12 times per year</p>
<p><u>Funding over 50k</u> Initially on a monthly basis for the first two months and thereafter 3 times per year</p>	<p><u>Funding over € 50k</u> Initially on a monthly basis for the first three months and thereafter 4 times per year</p>	<p><u>Funding over € 50k</u> Initially on a weekly basis for the first- month followed by fortnightly reporting for two months. Thereafter 12 times per year</p>

Table 9: Frequency of formal reviews of the *Outcomes for budget holder*

Level 1 Governance (Low)	Level 2 Governance (Medium)	Level 3 Governance (High)
<p><u>Funding of < €20k</u> Year 1 – 1 review Year 2 – 1 review</p>	<p><u>Funding < €20k</u> Year 1 – 1 review Year 2 – 1 review</p>	<p><u>Funding < €20 k</u> Year 1 – 3 reviews Year 2 – 2 reviews</p>
<p><u>Funding € 20-50k</u> Year 1 – 1 review Year 2 – 1 review</p>	<p><u>Funding € 20-50k</u> Year 1 – 2 reviews Year 2 – 1 review</p>	<p><u>Funding € 20 – 50k</u> Year 1 – 4 reviews Year 2 – 3 reviews</p>
<p><u>Funding over 50k</u> Year 1 – 1 review Year 2 – 1 review</p>	<p><u>Funding over € 50 k</u> Year 1 – 3 reviews Year 2 – 2 reviews</p>	<p><u>Funding over € 50k</u> Year 1 – 4 reviews Year 2 – 4 reviews</p>

In general terms, it is clear that under Level 3, the highest level of governance and oversight, there is a requirement for more frequent reporting and review of accounting and outcomes than at the other two levels. Similarly, where higher amounts of funding are approved there are more stringent reporting requirements.

7.4 Conclusions and Recommendations

7.4.1 Conclusions

Service providers and support workers recruited from a personalised budget should have completed relevant training in relation to delivering supports to people with disabilities. This should be aligned to the quality framework that will be published under Transforming Lives.

For the purposes of audit and to ensure that minimum standards are met, the Task Force recommends that the HSE create, maintain, and regularly update a list of approved service and support providers with whom a personalised budget can be used. This register should be used to verify that the support purchased with a personalised budget is paid to a person or organisation that is suitably qualified, Garda vetted and tax compliant.

7.4.2 Recommendations related to this Chapter

- The governance of personalised budgets will follow the guidelines outlined in Chapter 7 of this report. The level of governance will vary depending on the funding option and on the amount of the personal budget approved. (*Recommendation 5*)

8 Financial Considerations for Personalised Budgets

As indicated in the international evidence review presented in Chapter 2 the introduction of personalised budgets in other jurisdictions has in some instances, given rise to unforeseen additional costs, threatening the long term sustainability of these funding arrangements. This risk was noted by the Task Force at the outset and expert assistance was sought from the Department of Health's Research Services Unit to assess financial sustainability from a health and social care policy perspective.

8.1 Financial Sustainability - background

The World Health Organization concludes that while there is little clarity or consensus on a definition of financial sustainability the issue is often described as the ability of governments and others to adequately finance health care in the face of growing cost pressures. Population ageing, new technologies and consumer expectations of healthcare coverage and quality are the three most commonly cited challenges (WHO, 2009). The WHO cautions against viewing financial sustainability as a policy objective in its own right as it may place the policy focus on achieving fiscal balance, without regard for the consequences and this may distract attention from other factors contributing to fiscal imbalance, in particular efficiency problems. However, focusing on the attainment of health system objectives, subject to the requirement of financial sustainability, provides policy-makers with a range of criteria which can inform decision making. Specifically, presenting a choice of options within a framework of financial constraints can highlight the explicit trade-offs which may need to be made.

8.2 Risks that may affect financial sustainability

The additional or new costs associated with administering a personalised budget is a key issue regarding financial sustainability of personalised budgets. It is difficult to estimate this cost and this will vary depending on the choices made regarding payment options, governance levels, etc.

Important factors to be considered in relation to staffing include: industrial relations issues, difficulties in recruiting personal assistants (which may result in higher costs), risk of a two-tier workforce with regulated and unregulated personal assistants

Double-running costs (implementing personalised budgets alongside traditional systems) can arise as well as additional cost factors from unmet need, a risk of cherry-picking by private providers, use of personalised budgets to pay for items previously paid for out-of-pocket, family carers displaced by paid carers and potential fraud in both the assessment and payment phases.

Fraud in respect of personalised budgets may arise in relation to the assessment stage or during the implementation phase. The evidence indicates that fraud levels overall tend to be low and

that under spending is more common than overspending. Measures such as clear criteria and providing good training to assessors can reduce fraud at the assessment stage while online systems of payment and audit measures can minimise fraud during implementation. The research evidence suggests that while a high level of regulation does not necessarily enhance fraud reduction, it can act to dissuade participation in a personalised budget due to a burdensome level of administration.

Service users face potential risk from a possible decrease in HSE and HIQA oversight of the quality of care delivered by an increasing number of service providers. Notwithstanding a commitment to facilitate uptake by service users with all levels of support needs, the experience in the Netherlands suggests that there is a risk of introducing inequity with better educated / higher income service users or their families better positioned to access and navigate personalised budget systems.

From a service provider perspective there may be loss of economies of scale where a significant number of existing service users opt for a personalised budget and move to non-traditional providers. Similarly, sunk costs into existing systems and infrastructure may not be easily recovered if the number of service users and associated block grant decreases. Further risks can arise in relation to the number and/or skills mix of staff employed on permanent contracts.

8.3 Planning for initial demonstration projects- Costs and Financial Sustainability considerations

The initial demonstration projects will be important not only guiding on necessary systems, structures and processes, but also in informing the costs involved and financial sustainability. Factors for analysis in the initial demonstration projects include the range of services provided through a personalised budget (from a limited choice, to suite of core services, to an extensive choice of services), the quality of the services provided, whether the services are centralised or decentralised, the flexibility and choice for users and the speed of access to these services.

As staffing and associated pay-related expenditure are the biggest cost component issues to consider, the volume of staff along with factors such as location (centralised vs decentralised), type and grade of staff (which in turn is dependent on decisions around type of services, level of choice, access, quality etc), substitution and skill mix, quality and choice should all be monitored in demonstration projects.

Research suggests that a potential downward force on costs in relation to staff may be seen through substitution of staff from higher to lower grades. However, existing contractual arrangements for employers may mean that they have limited flexibility in the shorter term to substitute staff in higher grades doing work which could be delivered by others at a lower grade. In the mid- to longer-term this would typically be less of a constraint.

A key consideration in relation to cost will be 'who' is doing the governance. If the budget holder can manage their own governance arrangements the per-hour costs would be expected to be at the lower end of the scale. If governance is supplied through a third party or a governance 'expert' (e.g. a chartered accountant with specific and relevant experience) the per-hour cost and total cost would be expected to be at the high end of the scale. If governance arrangements are high-involvement, i.e. involving many hours occurring periodically, this will increase total costs but will have lower risk.

8.4 Suggested indicators to guide planning and evaluation of demonstration projects

With respect to financial sustainability, appropriate data collection and information gathering in the initial demonstration projects can provide valuable information on:

- The impact of service user take-up of personalised budgets on the system and how this impacts costs of service delivery.
- The impact of changes in delivery of services to service users by providers on their capital costs, capital investments, pay costs and non-pay costs of service provision including identifying the reality of unbundling, and the administrative costs and challenges of doing so.
- The aggregate impact on the delivery of the system of disability services.

8.5 Conclusions

8.5.1 Conclusions

All of the evidence reviewed highlights the need for transitional and set-up funding to develop new systems, train staff and to test and evaluate the new processes. Change should be introduced over a fairly long period of time using a strategic and phased approach with a focus on depth and quality rather than scale.

A single national system of personalised budgets is likely to provide economies of scale in comparison to multiple local or regional systems. In addition, in some countries with a decentralised funding and decision making model there was some inequality in access to services.

A key finding from the international experience is that personalised budgets systems can become financially unsustainable if introduced without adequate risk mitigation measures.

Market development may need to be undertaken by the system funders if service users are to be offered meaningful choice. In order for brokerage services to be cost effective an adequate number of service users and a geographical focus may need to be considered.

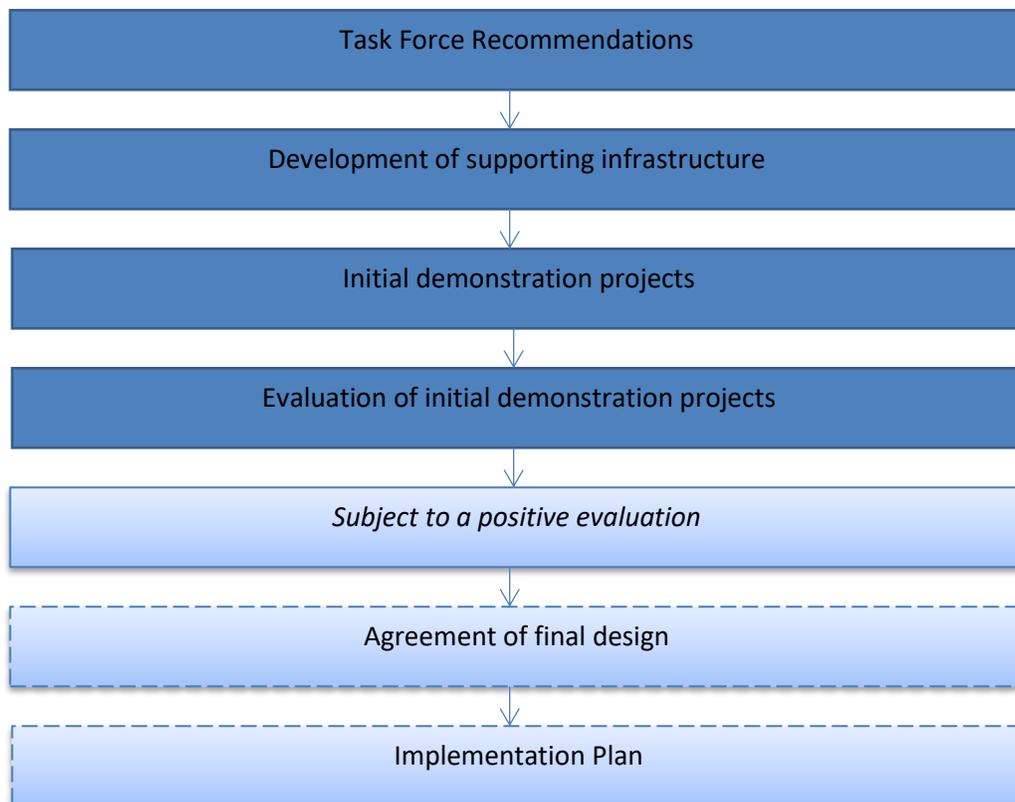
9 Moving Forward with Personalised Budgets

9.1 What the next steps towards implementation should be

This report records the wide range of conclusions and recommendations that the Task Force were able to form as a result of its work. A framework is recommended that sets out the broad principles that are required to underpin the introduction of a national system of personalised budgets. There are also a number of areas where further data and research is required before final conclusions can be made.

9.1.1 Demonstration Projects

It is the view of the Task Force that there will need to be a number of initial demonstration projects to test the various governance and payment models for personalised budgets outlined in this report. It will only be possible to complete the financial sustainability piece of the work allocated to the Task Force once there are real models available in an Irish context, with a comprehensive set of data to measure the outcomes against. The diagram below sets out the sequencing of the development of the initial demonstration sites. This process is projected to take in the region of two years to complete.



9.1.2 Evaluation of initial demonstration projects

The Task Force is of the view that the final design of any system of personalised budgets in Ireland can only be decided upon once the initial demonstration projects have been evaluated and the findings assessed, alongside the outcomes achieved by the person and the financial sustainability of the system as a whole.

Detailed variables to consider as part of demonstration projects include service-user characteristics, scheme characteristics and other measures such as outcomes, geographical variations, substitution, price variation and competition etc. The demonstration projects should reflect the challenges relating to rural areas and community inclusion. As well as information on the operational costs of a personalised budget, data should be gathered on user experience, improved quality of life outcomes or greater flexibility. The design of the demonstration projects should also include systems for evaluation from the outset.

There will be initial set-up and transition costs in introducing a model of personalised budgets. The initial demonstration projects will need to track the cost of necessary systems and infrastructure in place to manage, monitor and measure all aspects of personalised budgets. These considerations should be reflected in the evaluation of the demonstration projects, which should also include consultation with the key stakeholders involved in the projects

Education and training and capacity building will be critical to support and sustain any model/s of personalised budgets. Therefore, it will be important to consider the infrastructure, systems or resources that need to be put in place, the lead-in time to deliver same, and to consider how these might change over time. The supports will need to be flexible and capable of being adapted to reflect the nature of a disability and the level of need, including being capable of adapting to acquired disabilities and progressive, episodic or changing needs.

As there are currently no pure brokerage models currently in place in Ireland, there is a need for market development in this area. This will need to be monitored to assess the costs and effectiveness of difference brokerage services.

“Unbundling” of funding from existing services remains a significant challenge for the disability services, and it will need to be considered further as part of the demonstration phase.

The implementation of personalised budgets should be monitored and the learning shared through the National Disability Inclusion Strategy (NDIS) reporting mechanisms. Implementation on this Strategy is overseen by a Steering Group chaired by the Minister of State, with representatives of relevant Departments and agencies and of disability stakeholders.

9.2 Additional considerations

It is important that a personalised budget have a sound legal basis to ensure that monies from personalised budgets are not seen as income for tax purposes, means assessment etc.

One question that has arisen is how a personalised budget would be treated for the purposes of a means test for social welfare payments. In our view, a personalised budget, as currently envisaged, should not be considered as income support as it is effectively an alternative to directly provided HSE-funded services. Any payments provided should not be regarded as income for the purposes of social protection payments, medical card or other income related supports and this should be reflected where possible in legislation. The Task Force is of the view that this is also true for the purposes of Revenue considerations. This may also impact on how a system of personalised budgets would interact with court awards for compensation or insurance payouts.

If a direct payment model of personalised budgets is rolled out in the future, it is the view of the Task Force that this payment should be into a separate bank account from the personal bank account held by the person with a disability for governance and oversight purposes. This should also assist in ensuring that only transactions associated with the personalised budget are recorded and are easily distinguishable for both practical and audit purposes.

In cases where the value of a personalised budget exceeds the thresholds laid down for public procurement, (e.g. if there is a requirement for advertising on e-Tenders or in the OJEU¹⁸) this would add a significant administrative burden and may need to be managed centrally by the HSE.

At this point, it is unclear what role, if any, HIQA will play in relation to personalised budgets. Ongoing engagement with HIQA will be required as there are a number of supports that are most likely to be purchased using a personalised budget that are not currently regulated by HIQA, but may be in the future (e.g. draft interim standards are in place for day services, but these are not currently inspected by HIQA).

The Department of Health is developing a new scheme that will improve access to the home care services that people need, in an affordable and sustainable way. The Department will also introduce a system of regulation for home care so that the public can be confident that the services provided are of a high standard. The way that the new scheme and regulations will interact with personalised budgets will have to be considered.

It is recognised that current HSE-funded disability supports are typically provided through funded service providers as provided in legislation. Regulations or guidelines to support the direct payment model may need to be considered at a future date, depending on the outcomes of the initial demonstration projects.

9.3 Areas where members of the Task Force held differing views

¹⁸ Details of thresholds that apply to various types of contract are available at [etenders](#).

Members of the Task Force held differing views on whether some flexibility should be allowed for a small amount of discretionary spending. While this spending might align with the goals of the support plan it would not feature in the agreed spending plan or might fall outside of the typical areas on which a personalised budget could be used. It was agreed that this would be kept under review for future phases of the roll out of personalised budgets.

The Task Force also did not hold a shared view on the topic of hiring family members with personalised budget monies. Some members of the Task Force felt that this should be permitted, some felt that it raised governance issues, potential conflicts of interest, and potential to undermine whose choices are being made - the individual with a disability or the family member's. In the absence of an agreed approach, this will not be permitted in the case of the initial demonstration projects.

9.4 Potential areas for future expansion

While the initial focus is on personalised budgets in lieu of disability services for adults, the Task Force recommends that subsequent phases of work examine extension to other areas of public service, including disability services for children, building on the work of this Task Force.

A separate paper has been prepared to note views in this regard that emerged over the course of the project that are outside the scope of its work.

9.5 Recommendations

- A key action in moving to personalised budgets is to undertake a planning and testing phase. The Department of Health and the HSE should establish demonstration sites to test the delivery of personal budgets e.g brokerage models, direct payments etc. with a view to identifying the best approach to the wider roll-out of these payment models following the initial demonstration phase. (*Recommendation 10*)
- The demonstration projects should also test a range of issues such as the costs of operating a personalised budget for the individual, quality assurance, employee management issues, governance arrangements and financial sustainability in the Irish context in accordance with the recommendations of the Task Force outlined above. (*Recommendation 11*)
- The demonstration projects should be implemented over a two year period from the date of publication of the Task Force Report. (*Recommendation 12*)
- A formal evaluation of the Demonstration Projects should be completed and submitted to the Dept. of Health at the end of the two year period. (*Recommendation 13*)

- The Department of Health should assess the evaluation report and make recommendations to Government on the next steps regarding roll out of personalised budgets. (*Recommendation 14*)
- Learning from the demonstration sites should inform the development of guidelines required to enable further implementation of a personalised budgets system. This should include specific provisions to support the introduction of a direct payment model of personalised budgets and graded levels of accountability. (*Recommendation 15*)
- In conjunction with the Department of Employment Affairs and Social Protection, the Department of Finance and the Department of Public Expenditure and Reform, the Department of Health should examine whether legislative change may be required to ensure that a personalised budget is not subject to assessment as income or means-tested for the purposes of the Finance Acts or Social Welfare Acts, or for other income tested schemes. (*Recommendation 16*)
- The Department of Health should report progress on the development and implementation of personalised budgets under the National Disability Inclusion Strategy. (*Recommendation 17*)
- The outcomes of the demonstration projects should be shared with other Government Departments, who may wish to consider the potential to implement personalised budgets in their sector. (*Recommendation 18*)

10 Appendices:

10.1 Supporting Documentation (available on Department of Health website)

Advice Paper on supports to apply for and use personalised budgets – Report prepared by the Advisory & Consultative Group

Easy Read Version of Personalised Budgets Consultation Questions -Prepared by ACE Communication

Easy Read Version of the Report on the Personalised Budgets Consultation Process - Prepared by ACE Communication

Financial Sustainability of Personalised Budgets, A document compiled by the Research Services Unit, Department of Health, for the Task Force on Personalised Budgets

Introducing Personalised Budgets for Persons with Disabilities in Ireland – Report prepared by ALPHA

List of Membership of the Advisory & Consultative Group

List of Membership of the Strategy Group

List of organisations represented at the Regional meetings

List of organisations who participated in the written submissions

National survey on the prevalence of personal budgets – Report prepared by the National Disability Authority

Personalised Budgets Consultation Questions – Prepared by Task Force Secretariat

Project Initiation Document

Report on the Personalised Budgets Consultation Process

Synthesis Paper on Personalised Budgets – Report prepared by the National Disability Authority

Terms of Reference for the Advisory and Consultative Group

Terms of Reference for the Strategy Group

Work Plan Developed to assist the Task Force with its mandate

10.2 Task Force Membership

10.2.1 Strategy Group Membership

Name	Organisation / Role
Christy Lynch	Chair of the Task Force
Siobhan Barron	Chair of the Advisory & Consultative Group
John Bohan	Department of Social Protection
Patsy Carr	Department of Health (April 2017 - Present)
Claire Collins	Department of Health (May 2017 – Present)
Gráinne Duffy	Department of Health (Until April 2017)
Anne McGrane	Department of Health (Until May 2017)
Owen Collumb	Áiseanna Tacaíochta
Paddy Connolly	Inclusion Ireland
Sarah Craig	Health Research Board
Eithne Fitzgerald	Independent member
Aideen Hartney	National Disability Authority
Barry O’Brien	Department of Public Expenditure and Reform
Judith Merimans	Department of Public Expenditure and Reform
Gary Lee	Independent member
Joanne McCarthy	Disability Federation of Ireland
Gerry Maguire	Special Advisor to Minister McGrath
Marion Meany	HSE Disability Strategy
Clodagh O’Brien	Not for Profit Business Association
Brian O’Donnell	National Federation of Voluntary Bodies
Jennifer O’Farrell	Department of Justice & Equality
Gerard Quinn	NUIG Centre for Disability Law and Policy
Brian Hayes *	Advisory & Consultative Group representative
Rachel Cassen**	Advisory & Consultative Group representative
Kieran Cashman	Secretariat, Department of Health
Joanne Clarke	Secretariat, Department of Health

Martin Naughton was appointed to the Strategy Group in recognition of his expertise and experience in the area of personalised budgets, but sadly passed away on 13th October 2016. Ar dheis Dé go raibh a anam.

* Gordon Ryan is the alternate for this position, on the nomination of the Advisory & Consultative Group

** Teresa McDonnell

10.2.2 Advisory and Consultative Group Membership

Siobhán Barron (Chairperson of the Advisory & Consultative Group)
Sean Conneally
Teresa Accardi
Fionn Angus
Rachel Cassen
Gordon Ryan
David Girvan
Pat Clarke
Michael Doyle
John O' Doherty
Cathal Leonard
Denis Doolan
Bob McCormack
Padraic Fleming
Paul Fagan
Carol O'Donnell
Michael McCabe(June 2017)
Teresa McDonnell
Geraldine Graydon
Brian Hayes
Brigid Pike
Mary Doherty
John Hannigan
Anne Melly
Laura Enright
Sean Connick
James Cawley
Stephen Cluskey (Until April 2017)
Dharragh Hunt, National Disability Authority, Secretariat

10.3 Information on supports for self-managing a personalised budget

Becoming an employer	
<ul style="list-style-type: none"> • Basic Employment Law including the responsibilities of being employer and safe recruitment and employment processes 	<ul style="list-style-type: none"> • Doing the checks including references and Garda vetting
<ul style="list-style-type: none"> • Drawing up a job description 	<ul style="list-style-type: none"> • Health and Safety Training
<ul style="list-style-type: none"> • Getting public liability and employer's insurance 	<ul style="list-style-type: none"> • Contract of Employment how to draw up same
<ul style="list-style-type: none"> • Setting out the Tasks 	<ul style="list-style-type: none"> • Arranging staff induction and training
<ul style="list-style-type: none"> • Advertising the post 	<ul style="list-style-type: none"> • Agreeing a probation period
<ul style="list-style-type: none"> • Selection Process 	<ul style="list-style-type: none"> • Getting employer's indemnity insurance
<ul style="list-style-type: none"> • Interview Process and skills training 	<ul style="list-style-type: none"> • Data Protection
<ul style="list-style-type: none"> • Choosing the right person 	
Managing Money and HR Responsibilities	
<ul style="list-style-type: none"> • Payroll and related topics 	<ul style="list-style-type: none"> • How to manage salaries for employees
<ul style="list-style-type: none"> • How to set up a separate bank account 	<ul style="list-style-type: none"> • Understanding responsibility for Social Insurance, Tax and Pensions
<ul style="list-style-type: none"> • Understanding matters in relation to Statutory Leave and payments for same this should include Sick Pay, Holiday Pay etc 	<ul style="list-style-type: none"> • Ensuring back-up available to cover holidays, sick leave, and in emergencies
<ul style="list-style-type: none"> • Reporting to Revenue, how to register for Revenue On-line, issuing P60s 	<ul style="list-style-type: none"> • Rosters
Performance Management	
<ul style="list-style-type: none"> • Understanding how to ensure that support needs are meeting the agreed outcomes as identified in the personal support plan 	<ul style="list-style-type: none"> • Ensuring tasks are being performed as agreed and laid out in the job description
<ul style="list-style-type: none"> • Supervision of staff 	<ul style="list-style-type: none"> • Conflict Resolution
<ul style="list-style-type: none"> • Understanding of Grievance and Disciplinary Procedures 	
Reporting Requirements	
<ul style="list-style-type: none"> • How to keep an employee record and report on same 	<ul style="list-style-type: none"> • Time sheets
<ul style="list-style-type: none"> • Reporting on budget spend to funder 	<ul style="list-style-type: none"> • Reporting agreed outcomes

10.4 Note from Advisory & Consultative Group on possible future areas for extension of personalised budgets

The Taskforce was tasked with considering a model of personalised budgets that would provide adults with disabilities more control and choice with regard to how they would use a personal budget to purchase supports that would be funded within the HSE personal social services budget.

While it is recognised that the concept of personalised budgets is not limited to health and personal social services and that the approach would mean that a policy would commence in this area only, views on areas that could be considered in the future were also noted through the work of the Task Force and wider consultation, as follows:

- Children with disabilities.
- Aids, appliances and assistive technology.
- Education Supports.
- Employment Supports.
- Transport.
- Home supports that enable independence.
- Clinical (psychology, social work, medical) and therapy (Speech and Language, Occupational and Physiotherapy) services, as well as alternative therapy services.
- Wealth accumulation strategies.