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Policy Briefing No. 2

A Quarterly Production of the CDLP

July 2010


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What Are Policy Briefings?

The Centre for Disability Law and Policy hosts and sponsors a large amount of comparative law and policy research focused on disability. Much of this research is directly relevant to current policy challenges in Ireland.

The Centre is committed to providing succinct Policy Briefings on a quarterly basis which summarise some of its relevant research and tie it directly to these policy challenges. This is the second in that series. It is intended as a public service to make the public aware of innovative policy solutions adopted elsewhere in the world that may enrich debate in Ireland. We hope you find it useful. Please visit our website for further information on research underway and please log on to our Disability Law Blog (on our website) for up-to-date news of relevant to policy debates in Ireland.

We welcome comments, questions, suggestions and feedback. Please direct your comments to info.cdlp@nuigalway.ie
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1. **Focus of this Policy Brief**

The following brief outlines the individualised resource allocation systems currently being used in the UK, various states in the US and various provinces in Canada. It then examines the funding model in Ireland and considers the extent and potential for developing an individualised funding model in the Irish context.

Individualised funding refers to all cash payments made to individuals to purchase services, including direct payments and individual budgets, whether these are made through a third party or not.

While some of these individualised funding systems include Direct Payments, it is important to state that direct payments are only one option along a spectrum of individualised funding models.

As well as identifying the models being used, this policy briefing also examines the challenges which have arisen in each jurisdiction and lessons being learned from the application of each model. These are presented in the recommendations section.
2. **Individualised Funding Models in the US**

Individualised funding programmes in the US are generally referred to as ‘Self-Determination programs’. They are paid through Medicaid waivers at State level. As a result, every state has a different Medicaid waiver. However, the Federal Centre for Medicare/Medicaid Services (CMS) encourages the use of individual budgets to help individuals using waiver services to exercise increased self-determination.

In states that piloted individual funding, it was recognised early on that there was a need to build in a variety of levels of support for managing services and finances. Most self-directed programs now offer the services of an *Independent Consultant* (IC) and a *Fiscal Intermediary* (FI). These are generally funded through state expenditure and are expected to work closely with the individual and with each other.

An IC is generally required to help the individual create a supports and services plan and help put that plan into action. They are familiar with community resources and the state’s long-term care systems.

A FI is generally required to collect and account for the individual’s monthly Medicaid cost share or spend down if they are required to pay one, and provide the individual with assistance, including processing paperwork and time sheets, when they employ workers directly.

The following two models demonstrate how individualised funding has been developed in two different states, firstly IRIS in Wisconsin and the DOORS model in Wyoming:
IRIS, Wisconsin

IRIS (Include, Respite, I Self-Direct) is a Wisconsin program offering Self-Directed Services to individuals with developmental disabilities, physical disabilities, and those who are ‘frail elderly’. It is an umbrella body similar to a Managed Care Organisation, which gives funding to individuals, who can use the money to buy services from provider agencies.

Everyone receiving an individual budget from IRIS has an IC from their Independent Consultant Agency (ICA). The IC is required to meet with the participant a few times each year. The participant may choose to have more meetings if they need additional help. IRIS also has a Financial Services Agency (FSA) to help participants with the financial aspects of managing their individual budget. The ICA and FSA are provided at no cost to monthly budgets. The Department of Health and Social Services pays the cost for both ICA and FSA outside of the participant’s monthly allocation amount.

All IRIS participants develop a written Supports and Services Plan with their IC. The IC is trained in assisting the individual (and their family if necessary) to develop a support plan based on the individual’s wishes and goals.

The Individual Budget Allocation (IBA) is then based on Wisconsin’s “Functional Screen” for everyone who may need long-term care services from IRIS. Most of the significant questions in all three models (elderly, intellectual disability and physical disability) involve activities of daily living. The dollars assigned has to be explained by needs and characteristics of the person served and supported and the methodology has to be the same for everyone in each of the three groups of waiver participants. The model was built to calculate a projected monthly budget allocation for each person who selects IRIS as the way he/she will receive
and manage his/her publicly funded long-term care services and supports. Wisconsin continue to extensively refine their new model.

As a result, the individualised monthly amount for each person is based on the following factors:
- Activities of Daily Living
- Functional Status
- Health
- Predicted ongoing services cost
- Matching of MCO spending for similar persons
- Geographic adjustment
- Medicaid Card Services and infrequent use services excluded
- Significant change in condition adjusts allocation
- Annual cost of living adjustment

An individual’s Functional Screen is updated at least once every year. If there is a change in their abilities or needs, their IRIS allocation may change too. They can ask for a new Functional Screen if their health or abilities change, and that change will last for more than three months.

In terms of agreed expenditures, there is an approved shopping list of expenditures available (see attached on p.11). Individuals also retain access to all Wisconsin Medicaid State Plan Services including medical, dental, prescriptions, in-patient hospitalization and medically oriented services. These costs are not included in the Individual Budget Amount. As well as agreed services, there is also the option of paying for “Customized Goods and Services”. This refers to a flexible category of goods or services that gives the participant the chance to be creative when deciding how to best accomplish their goals. In addition, there is also the option to pay for short-term needs through the “Exceptional
Expense Fund” in limited circumstances, such as a short-term increase in needs, a relocation in housing, etc.

The IBA excludes regulated residential care (Adult Family Homes (1-4 beds), Community Based Residential Facilities (CBRF), or a Residential Care/Apartment Complex (RCAC)). This is paid for through a different Long-Term Care Program. Therefore an individual’s room and board, including their rent, mortgage payment or utilities are excluded from IRIS individual budget amounts. Payment for room and board expenses are specifically prohibited within federal Medicaid regulations.

An individual can use more in some months and less in others as long as the services are listed on their plan. They may also shift budgeted dollars between services listed on their plan at any time. They may set aside money for purchases up to 12 months in the future as long as those goods, supports and services are listed on your Support and Service Plan.

If an individual has tried to create a plan and finds that their IRIS allocation is not enough, then their IRIS Consultant prepares and submits an Allocation Adjustment request to the Department of Health Services for review and approval. In cases where an individual needs a short-term or one-off increase in their supports or services, their IRIS Consultant prepares and submits an Exceptional Expense request to the Department of Health Services for review and approval.

In terms of how much a participant or his/her family are willing to manage as well as govern the individual funding, there are a number of options available along a spectrum of involvement for obtaining support. This is illustrated below:
Table 2.1: Continuum of Involvement in Management of funding

<table>
<thead>
<tr>
<th>Less Self-Direction</th>
<th>More Self-Direction</th>
</tr>
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<tbody>
<tr>
<td><strong>You Buy Agency Services</strong>&lt;br&gt;The agency chooses, employs and manages the workers. The IRIS Financial Services Agency pays the agency invoice.</td>
<td><strong>You Recommend Workers</strong>&lt;br&gt;The workers you recommend are employed and managed by the Co-employment or Leasing Agency. The IRIS Financial Services Agency pays the agency invoice.</td>
</tr>
<tr>
<td><strong>You Manage the Workers</strong>&lt;br&gt;The workers you choose are employed by the Agency With Choice Provider. The IRIS Financial Services Agency pays the agency invoice.</td>
<td><strong>You are the Employer</strong>&lt;br&gt;You make all employer decisions. The IRIS Financial Services Agency is your employer agent and handles all payroll tasks.</td>
</tr>
</tbody>
</table>

(Source: adapted from IRIS handbook)

Importantly, the transition to IRIS was a complex process. Wisconsin had to implement a New Blended Model of IRIS and other long-term care programs, so that both could co-exist. The state made a clear mandate of cost-neutrality for the new IRIS program, which meant that IRIS had to be careful to not go over budget. This process was achieved by the use of the newly developed IRIS individual budget allocation model beginning promptly in July 2008 accompanied with a rigorous and long-term plan for refining and improving this new, but solid, individual budget model during the next five years.

In terms of designing the IBA, the consulting company Waterhouse and Price developed the predictive models for the three target groups. The group studied literature related to the development of similar tools in other states. To ensure cost-neutrality, they used the 2006 Family Care (other long term care program) cost history for the basis of comparison. The average approximate Family Care monthly cost history was $2,350. For the individual recipient of an IRIS IBA, the following pieces of funding were taken out and retained by IRIS (and the state for Licensed Residential Service Costs):
Subtract 6% administration (130)
Subtract 15% care management (330)
Subtract Medicaid Covered Services provided within FC (680)
Subtract Licensed Residential Service Costs (700)
Subtract one time only funds ( 20)

This meant that the total average available for IRIS Services within the waiver was $ 490 per month. Variance in this amount was also estimated, based on the indicators used and previous service history, with some above the amount (estimated at 61%), some equal to the amount (estimated 6-9%) and some below this amount (estimated at 31%).

For new individuals with no cost history, state staff used the original IRIS individual budget method for people moving into services for the first time. However, continual review of the IBA has been used to form the Amended IRIS Individual budget Allocation Method. This has allowed IRIS to gradually build a legacy of increased explainability of people’s costs related to their needs.

More details on the allocation methodology available at:
### DOORS model, Wyoming

As well as IRIS’ model of individualised funding, the DOORS model in Wyoming is also credited as having a pioneering resource allocation methodology for adults with Intellectual disability based on a *unique*
Individual Budget Amount (IBA). The DOORS IBA combines objectively assessed individual characteristics as well as a persons’ service utilisation.¹

Importantly, their previous model of five standardised levels of funding and local negotiation with providers proved not to work well. This approach led to a weak correlation between the individual’s needs and their funding amount. Small differences in scores could also result in major differences in the money available to support individuals, which led to much more complaints and requested reviews. Moreover, the previous model only accounted for 37% of variability in IBA between individuals.

This rate of variability rose to 75% with the DOORS model. In other words, there was a substantial increase in the association between individual service users’ assessed support needs and the amounts of funding provided to meet those needs. Rather than grouping individuals by broad scores (as it had previously had done), the DOORS model generates person-by-person budget amounts. The policy adopted was that funding should be tied principally to indicators of individual need rather than linked to provider characteristics or service modalities.

The combined set of indicators include *inter alia*:

- Age
- Type of disability
- Level of disability
- Social Communication score (including challenging behaviour)

• Frequency of seizures
• Lives with family?
• Lives independently?
• Independent with monitoring?
• Residential services received?
• Day habilitation received?
• Personal care received?
• In-home services received?

The scores for each of these indicators are then weighted, and the overall result calculates a *unique* individual budget amount. As a result of Wyoming’s new model, there has been a reduction in complaints and a more accurate needs-based allocation of resources.

### 3. Individualised Funding Model in England

Direct Payments and individual budgets in England were introduced with the Community Care Act 1996. Since then, the government has been very proactive in promoting the use of direct payments for *all* health and social care.

There are four main models of funding in the UK\(^2\): block funding from the Social Care budget, the Independent Living Fund, Direct Payments, and Individual Budgets:

1. Block funding from the Social Care Budget pays for residential and associated care costs (e.g. group homes);

\(^2\) There are also a number of additional funding streams, including the Supporting People fund, Access to work funding and Disabled Facilities Grants, which can be included in a person’s individual budget.
2. The Independent Living Fund (ILF) is a Department for Social Security cash payment for purchasing care from an agency or employing a personal assistant;

3. Direct Payments (DP) are Local Authority payments to individuals to buy personal assistant hours (primarily, but not solely for people with physical disabilities);

4. Individual Budgets (IB) are Local Authority payments based on an individual’s package of care (primarily, but not solely for people with intellectual disabilities).

Firstly, the social care budget is the largest source of health and social care funding for the commissioning of blocks of support to providers. It pays for an entire package of care including residential and support services. While this budget has historically been seen as a ‘block grant’, some progressive Local Authorities such as Lancashire have worked with providers in designing individual budget amounts within a service out of the social care budget pool.³ Each person’s money is treated as a ‘restricted fund’ so the provider must account for it individually and must use it to benefit the individual and any shared use of support must be part of an agreed plan. The provider charges each person a 10% management fee, but beyond that it does not take out any further money from the person’s fund. It is also now agreed that the providers can sub-contract with other preferred providers services if they are more able to provide specific aspects of a person’s support.

Secondly, the ILF involves the Department for Social Security (DSS) making discretionary cash payments directly to disabled people so they

can purchase care from an agency or pay the wages of a privately employed Personal Assistant (PA). The ILF was originally established in 1988, intended to run for 5 years. When the original Fund closed in 1993, two new Funds were created. The Extension Fund was created to administer the payments of people who applied between 1988 and March 1993 and who continued to receive awards under the old rules. The 1993 Fund was created with slightly different rules - mainly, the condition that Social Services should provide a weekly financial contribution - to take on new applications. By 2006, there were over 18,000 people using the ILF across the UK.

Thirdly, DP’s emerged from continuing pressure from the (largely physical) disability movement and the publication of research demonstrating the cost effectiveness of direct payments. This led to the culmination of the Community Care (Direct Payments) Act 1996, which allowed direct payments. Having resisted direct payments for many years, the governments of the UK and the devolved administrations now strongly promote direct payments in their policy, as articulating with both the social justice and modernizing welfare agendas.

Finally, in intellectual disabilities, and to a lesser extent, mental health, there was less scope for utilising direct payments, particularly for those

tied into residential service arrangements with commissioned providers. In response, an organisation called In Control developed a piloting exercise to individualise a support care budget in 2003. This led to the development of Individual Budgets, which are based on a broader package of care support needed to allow an individual live in the community.

The Local Authority is responsible for commissioning services in the UK. As a result of the different funding streams, disability provider organisations often receive their funds through different means. The Local Authority can provide a block grant from the social care budget to commission a block of support (e.g. 15 places within group homes). To enable the use of DP/IB’s, the Local Authority can also design a Framework (Zero Volume) Contract with providers in their jurisdiction. This latter approach allows the local authority to set criteria on best practice for providers to operate in their area. In this case, the contract does not accord any funding directly to the organisation. Instead, individuals with DP/IB’s are able to access support from providers who have complied with these contracts. This allows the Local authority to maintain some leverage over the quality of providers in their area.

This mixed-method means that organisations can sometimes get part funding for a discrete block of support (including the use of mini-tenders) and get the rest of their funding through individual’s direct payments. Given the potential increase in separate invoices from individuals with DP/IB’s, this can increase the need for back-office support in managing individual accounts, invoicing and non-payment. Some providers have also had to invest significantly in their IT systems to prepare for a larger-scale system of personal budgets.
In terms of resource allocation methodology, direct payments are based on the need for personal assistant hours. For individual budgets, the process is somewhat more complex, given the fact that IB’s pay for a wider package of care support options. In Control have developed a Resource Allocation System (RAS) for individualising budgets which many local authorities use across the UK. In Control has been developing their RAS methodology since 2003, and its model is currently in its 5th phase (from 2007). The individual develops their own Support Plan which sets out how they are going to live their life. This then goes for approval by a social worker. The indicators derived from the Support Plan scored assessment questionnaire (SAQ) are used in deciding the individual budget amount.

The SAQ measures the impact of a person’s disability on their life (functional assessment rather than impairment type assessment) in a number of key areas. For a look at the indicators used, see the self-assessment template link below. Each indicator is scored and the total is adjusted according to the amount of support reasonably available to each person from their friends and family. In this way people with similar levels of needs in similar circumstances can be allocated the same level of funding, and guaranteed the same outcomes. The RAS then works out an indicative sum of money from the self-assessment questionnaire. This gives the individual an idea of what the money is likely to be. It is an indication of what is fair and reasonable. When the person knows the indicative amount, they need to make a support plan that shows how they intend to use the money. A care manager or social worker at the

local authority then assesses the support plan and allocates the level of funding based on their assessment. Given that the RAS methodology has developed over time, each level of funding is based on local intelligence about how much money has been needed for people in similar circumstances to meet their agreed outcomes.

More generally, the method used can vary by local authority. It is widely recognised that some local authorities have developed more progressive commissioning models than others. Local Authorities such as Richmond, Oldham, West Sussex, Hartlepool, Cambridgeshire, Newham, Cumbria, Hampshire and Southampton have embarked upon large-scale whole systems change.

Overall, according to the UK governments own evaluation\(^8\), IB’s have been found to produce higher overall social care outcomes given the costs incurred (i.e. they are more cost-effective), but no advantage in relation to psychological well-being. They also have the potential to be more cost-effective than standard care and support arrangements. The cost-effectiveness advantage of IBs looks clearer for people with mental health problems and younger physically disabled people than for older people or people with learning disabilities. For this last group, however, implementation delays may have played a part: once support plans were in place, there was a greater likelihood that IBs were a cost-effective alternative to conventional arrangements.

4. **Individualised Funding Model in Canada**

Individualised funding is available in a number of provinces in Canada, including Ontario, under the Social Inclusion Act\(^9\), and British Columbia (BC) under the Community Living Authority Act. Given the recent passing of the Social Inclusion Act, implementation of individualised funding in Ontario remains in its infancy. This section therefore focuses on individualised funding in BC.

Since 2005, in BC, Community Living British Columbia (CLBC) is the statutory agency (Crown Corporation) responsible for commissioning services and supports for people with intellectual disabilities. In CLBC, individualised funding (IF) is available through a Direct Payment option or a Host Agency Funding payment option. Individualized Funding is used to purchase supports and services for the individual as agreed to by the individual, agent and CLBC.

Individuals and families who are interested in learning about or requesting Individualized Funding contact a CLBC *Community Living Centre*. CLBC’s two main staff groups are Facilitators and Analysts. A CLBC *Facilitator* will provide information to the individual and family about IF to assist them in deciding which IF payment option will best meet their needs. An Individual Support Plan is required and the plan must be developed with the assistance of a CLBC facilitator. An *Analyst* then reviews the support plan and allocates funding and / or services. The analyst is also responsible for ensuring effectiveness of the contracted service delivery system. This includes working with service providers to increase their capacity and supporting resource development through

\(^9\) Officially called ‘Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008’
partnerships with agencies that support progressive person-centred approaches

Individuals and families can select a combination of options including Direct Funding, Host Agency Funding and/or contracted services. Host Agency Funding is only available as a payment option when the request for CLBC funded supports is over $6,000.00 per year. Individuals and families who receive Direct Funding or Host Agency Funding can request a change to contracted services or the other IF payment option.

In terms of fiscal support with the CLBC IF system, the onus is on the individual to manage the budget. This is a complex process, particularly if the individual would like to become an employer of their support workers. Without a fiscal intermediary like in the US, this responsibility can be onerous for families and individuals with intellectual disabilities. As a result, IF is still a low demand option (84 families in 2008/200910).

The individual is expected to use some of their funds, up to the amount agreed to with CLBC, to pay for accounting or bookkeeping services to help fulfill these responsibilities. Under Direct Funding, the individual must seek the support of a financial agent to arrange, manage, monitor and report on the individual’s supports and services. The other responsibilities of an agent include:

a) administering and accounting for the money received from CLBC
b) working on behalf of the individual and representing his/her views
c) assuming a contractual relationship with CLBC

10 CLBC (2010) Service Plan 2010
Prior to the approval of a request for Direct Funding CLBC staff confirm whether the selected representative is capable of assuming these responsibilities. The agent and/or Host Agency are responsible for ensuring that the supports and services purchased with these funds comply with CLBC policies and program standards.

CLBC also must confirm that each individual participant uses the funds they receive as intended. Individuals are thus required to prepare and submit an electronic Financial Report each month to CLBC identifying how they have spent the money. To ensure that the Direct Funding continues uninterrupted, each individual must submit Financial Reports on time. Reports are due no later than 30 days after the end of the reporting period. CLBC will provide reminders of late reporting. After two written reminders followed by telephone contact, the individuals Direct Funding will be suspended until they have submitted all outstanding reports.

CLBC’s particular resource allocation methodology is not publicly available. However, generally, the amount of Individualized Funding allocated to an individual by CLBC is based on:
• the individual’s disability-related needs;
• the estimated cost of the needed supports’
• CLBC’s financial resources.

In terms of what the funding can be used for, it is for hiring support staff or to pay for other allowable expenses as outlined for each service listed on the individual’s schedule A – Supports and Services, as agreed within their plan. Additional types of supports and services funded by CLBC are determined by three internal policy tools, the Guide to Support Allocation of Resources, the Priority Ranking Tool and the Catalogue of Services (documents not publicly available). Some Support and Service
agreements may also provide “Variable” funding for events or situations that occur infrequently or the timing of their occurrence can not be accurately predicted. This Variable funding is used to pay for extra supports required by the individual during these times as outlined in the Schedule A – Supports and Services of the agreement.

5. Funding of Disability Support in Ireland:

The funding of disability support in Ireland comes from grant funding from the Health Service Executive Areas. In terms of the grants available through the service agreements, they are outlined through separate sections of the 2004 Health Act:

• Section 38 grants (old Section 26 funded organisations) relates to agencies / groups providing services on behalf of the HSE. This refers to services which the HSE is legally and statutorily required to provide and enters into an arrangement with an outside agency to do so on its behalf.

• Section 39 funding (old Section 65 funded organisations) relates to agencies / groups undertaking services which are similar or ancillary to those of the HSE and to whom the HSE is providing grant aid to do so. However the HSE would not be legally or statutorily obligated to provide such services.

In terms of Section 38 funding, there is an expectation that those in receipt of the grant are (non-profit) organisations, who deliver essential supports on behalf of the HSE. This means that the staffing, levels of pay, management etc are influenced by government, and the organisations are subject to making contributory pension arrangements for their staff. This is limited to 26 agencies currently within the HSE Employment Control Framework. However, there is generally little to distinguish the types of activities carried out within Section 38 or 39 disability organisations.
Often these could fall under either definition as outlined above (Section 38 & 39).\textsuperscript{11} For instance, many organisations that developed out of Parents and Friends Associations, but provide equally essential services, are often under the Section 39 funding stream, whereas many larger non-statutory organisations fall under Section 38.

Similarly, the distribution of expenditure within the mental health services appears to be historically and politically based and tends to follow the old mental hospital system rather than follow needs.\textsuperscript{12} Currently, levels of funding are not necessarily related to quality of care. Some areas with high funding maintain high levels of institutional care with poorly developed community-based alternatives. In fact, O’Keane et al.\textsuperscript{13} found that there was no clear relationship between financial allocation and the provision of clinical services. This raises issues about the resource allocation process generally across the country and the need for better data to ensure a match between personal circumstances and resource allocation.\textsuperscript{14}

For a long time there has been a tenuous link between funding levels and outcomes for people with disabilities. Allocations are generally made on the basis of the previous year’s outturn, the approvals to improve or expand services, and the availability of finance generally. There is often

\begin{itemize}
  \item \textsuperscript{11} Federation of Voluntary Bodies - HSE Policy and Procedures for Funding Non-Statutory Organisations http://www.disability-federation.ie/index.php?uniqueID=175
  \item \textsuperscript{12} Inspector of Mental Health Services (2004); Mental Health Commission (2005)
  \item \textsuperscript{14} O’Shea, E. and Kennelly, B. (2008) "The Economics of Mental Health Care in Ireland", Mental Health Commission, Dublin.
\end{itemize}
little connection between the size of the grant and the numbers catered for, the category of disability or the degree of disability. The grants are generally based on the previous year’s outturn.\(^{15}\) The State’s relationship with nonprofit organisations has evolved into one where services to persons with disabilities result from a historical pattern of provision and are largely negotiated rather than the result of contested procurement.

More recently, evidence of the lenient regulation of funding within the disability sector came to light in 2005, with a national audit of nonprofit disability service providers, by the Comptroller and Auditor General. Its report found a widespread failure among organisations, many of which were secular, to provide audited financial statements or disclose levels of executive pay.\(^{16}\) It also indicated that the introduction of service agreements varied in the geographical areas administered by the former health boards. In general, the service agreements were found to not relate the allocation to any measure of the service provided. The audit found that service agreements and provider plans differed substantially in format, content and detail of services to be provided from one nonprofit organisation to another. It also found that there are often weak or no links between core activity and funding. Service plans prepared by the former health boards did not indicate how services procured from nonprofit organisations would be aligned with those directly provided. Poorly-developed structures for monitoring, measuring and assessing performance levels in the context of statutory funding could, therefore, be said to exist.\(^{17}\)


\(^{16}\) Ibid.

\(^{17}\) Boyle, R and Butler, M. (2004) Autonomy vs Accountability – Managing Government Funding of Voluntary and Community Organisations,
While the Minister of State for Disability and Mental Health has signalled that individual funding could be a future policy option\(^\text{18}\), currently people with disabilities or mental health difficulties in the Republic of Ireland do not have a right to an individualised budget which would enable them to employ a personal assistant or buy support. Another outcome of this lack of commitment towards personalisation, is a culture where ‘service-users’ must not be exposed to unnecessary risk as services in many cases are dominated by procedures that aim to minimise risk.\(^\text{19}\)

Although there is no formal individualised funding system, to some extent there is enough flexibility in the system to establish individualised support arrangements that service providers have negotiated with their HSE areas. This system has been described as a “relaxed-control” model\(^\text{20}\), where decisions have become decentralised, service providers have a lot of autonomy, and there is little or no statutory oversight or regulation. In respect of the core-funding element, nonprofit organisations provide aggregated estimates in respect of ongoing services. As identified, the Comroller Auditor General examination found that, with a few exceptions, the level of supporting detail generally provided is minimal. New service developments and the costs associated with new client placements and enhancements, attract more consideration of costs than

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Institute of Public Administration.
\(^{18}\) O'Brien, C. (2010) "Disabled should get direct payments, says Minister", The Irish Times - Monday, April 26, 2010
the core-funding element.\textsuperscript{21} This type of funding effectively removes the promise of choice and control from people with disabilities and instead gives client capture to the providers. Control is therefore entrenched in the disability provider industry.

On the one hand, this provider-led system has led to some progressive service providers unbundling block grants themselves and delivering personalised support arrangements for their clients. In some cases, this has led to successful and innovative ways of rearranging funding, as well as linking in with mainstream services and developing home share arrangements. To aid this process, some providers, such as Sunbeam House for example, have conducted community services audits to compile a database of all available community services, which their clients can avail of and build connections with in their local area. In addition, an alliance of organisations committed to individualise their support has been established called ‘New Options Alliance’ in order to animate change, and support and ‘troubleshoot’ with each other on future transformation issues.

On the other hand, there are many parts of the country where providers have been reluctant to engage in personalisation, preferring to maintain traditional congregated care systems, with little or no opportunities to individualise support arrangements. Without a national strategy or innovative commissioning, many organisations remain reluctant or unable to design personalised support.

While the practice of locally developing individualised supports is to be celebrated, a more accommodating infrastructure and a national strategic vision, which would encourage this process, is lacking. Therefore, implementation of personalisation can vary substantially across the country. The practice has been quite ad hoc and discretionary, with best-practice being fragmented.

**Recommendations**

Given the potential scope of individual funding and proposed interest by the Department of Health in piloting this model in Ireland, this policy briefing aims to clarify some of methods used in designing individualised funding and to demystify some of its misconceptions.

The important lessons being learned from other jurisdictions in designing an individualised funding system include:

1. A new assessment tool will be required to evaluate individuals’ resource allocations based on the individual’s goals, the impact of their disability, their family circumstances, their living arrangements and so on.

2. An individualised allocation model based on objectively assessed individual characteristics rather than standardised bands of funding can provide a stronger correlation and more equitable relationship between personal need and funding level;

3. Individuals and families will need more facilitation and support in managing individual budgets. This is demonstrated by the need for Independent Consultants and Fiscal Intermediaries or host agencies;

4. Organisations providing individual supports for direct payments experience an increase in demand for back-office support
because of an increase in separate invoices and financial management;
5. Without proper built-in **flexibility** mechanisms, such as an “Exceptional Expense Fund” option, individuals who may experience temporary increases in need could potentially be put in vulnerable positions;
6. Individuals, their families and their host-providers will need to pre-plan **safeguards** and back-up support for the individual as part of their individualised support package;
7. The need for **more transparency** in the allocation of resources will be required than historically was the case;
8. A more **pro-active HSE role** will be needed in supporting providers, through collaborative relationships which promote good quality individualised practices;
9. A more rigorous **personal outcome evaluation framework** which feeds into organisational and HSE management will need to be developed.
10. The resource allocation methodology chosen will need to be **periodically reviewed** to ensure continual improvement and accuracy.
11. Given the research identifying the level of isolation and stigma of people with disabilities and mental health difficulties\(^\text{22}\), all stakeholders involved in supporting the individual need to prioritise **community connection** support (e.g. HSE community connector in Co. Clare).