**The Introduction of Individual Budgets as a Resource Allocation System for Disability Services in Ireland**

# A Contemporary Developments in Disability Services Paper

**May 2011**



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**List of Abbreviations and Acronyms**

AAIDD - American Association on Intellectual and Developmental Disabilities

ADASS - Association of Directors of Adult Social Services

AOS - Assessment Officers' System Database

CMS - Centers for Medicare and Medicaid Services

CQC - Care Quality Commission

HCBS - Home and Community Based Services

HIQA - Health Information and Quality Authority

HSE - Health Service Executive

HSRI - Human Services Research Institute

IBA - Individual-based Budget Allocation

I-CAN - Instrument for the Classification and Assessment of Support Need

ICF/MR - Intermediate Care Facility for People with Mental Retardation

LBA - Level-based Budget Allocation

MMIS - Medicaid Management Information System

NIDD - National Intellectual Disability Database

NPSDD - National Physical and Sensory Disability Database

RAS - Resource Allocation System

SIS - Supports Intensity Scale

SLOCC - State Level of Care Committee

# Executive Summary

The National Disability Authority is committed to providing evidence-based policy advice to promote community and independent living for people with disabilities[[1]](#footnote-1). NDA's vision is that people with disabilities are supported to live full lives, of their choosing, in the mainstream community. Specifically, NDA advises that better outcomes can be achieved for people with disabilities through the promotion of community integration, independent living, choice and participation; through the delivery of genuinely person-centred services to support people to live the life of their choosing; and through a change in the current funding of disability support services from disability organisations to individuals[[2]](#footnote-2). This latter outcome is the focus of this paper which aims to examine the issue of resource allocation of disability funding in Ireland.

The paper explores the current funding of disability support services in Ireland, examines the funding mechanisms operating in other international jurisdictions, and concludes with consideration of issues regarding the implementation of standardised resource allocation processes in Ireland. The paper is timely, as it coincides with the Review of the Efficiency and Effectiveness of Disability Services in Ireland under the remit of the Value for Money and Policy Review Initiative 2008-2011. Initial consultations from the Review suggest that major reform of disability service provision is welcomed, most especially the development of a model of individualised supports. A contributor to the Review reflected the call from many, including the National Disability Authority, for the introduction of self-directed services:

“the thinking and philosophy around disability has changed significantly over the last 10 years but services have not moved on. The current system is expensive…It is inflexible, the person or his/her family does not get to have much say in how the money is spent, or have a choice of service provider, and perhaps more importantly, the money is attached to the service not the person.”

The report comprises five chapters. Chapter 1 details the current situation in Ireland; Chapters 2 and 3, the experiences from both the UK and US respectively where individual budgets are widespread; Chapter 4 examines the mechanisms by which individual budgets can be calculated; and finally, Chapter 5 considers the next steps with regard to implementing a standardised resource allocation system in Ireland. Each chapter has been authored to stand alone; this may result in a small element of repetition. The following key summary points are elicited from the various chapters that comprise this report:

**Current Irish Situation:**

* The current system of funding disability services in Ireland is guided by the National Disability Databases. The role of these (and related) databases in supporting the development of self-directed services should be reviewed.
* Currently, almost three quarters of all disability funding is spent on residential and adult day care services.
* The funding of non-capital costs is conducted via Service Arrangements between disability service providers and the HSE. These new arrangements will provide more detailed information on service uptake and costs than has previously been available.
* Service Arrangements currently apply a traditional incremental determination process of block funding to disability service providers.
* Funding via commissioning, competitive tendering or individualised funding options is not available. Unit costs, where available, are based on historical staffing levels and not on level of support need.
* A number of recent reports by the Comptroller and Auditor General, Office of Disability and Mental Health and the National Disability Authority have called for the implementation of a more equitable individualised system of resource allocation in place of incremental determination processes.
* Recent reports examining resource allocation models across the wider Irish Health Sector call for a system that is based on need, is equitable and promotes individualised care solutions.
* The Assessment of Need process may provide the independent framework required for the development of individualised services and the allocation of individual budgets based on independently assessed need.
* A move from professionally-led clinical assessments to holistic assessments of support needs would reflect international trends.
* Ireland has 'late mover advantage' in implementing individualised support services for people with disabilities and will benefit from collaborations with those who have implemented these systems in other international jurisdictions.

**UK Experience:**

* The UK adult social care system is currently undergoing radical transformation towards a system of personalisation whereby individuals will have the right to have their needs assessed in a standardised manner, to be informed of the proportion of their support costs that will be paid for, and to use those costs in a portable manner irrespective of location.
* A Common Assessment Framework is being considered to coordinate and reduce duplication of assessments conducted in social care and related services.
* Assessments are moving from a traditional, professionally-led system towards a more individualised approach which is person-centred, completed in conjunction with carers, uses self-assessment tools, and is conducted within flexible timeframes.
* Local councils are obliged to offer eligible individuals the option to self-direct their own services and are currently in the process of implementing resource allocation systems based on personal budgets for non-residential social care. A target of 30% of eligible individuals transferring to personal budgets is set for March 2011.
* The determination of personal budgets uses a prospective model whereby an indicative budget is calculated prior to the development of a support plan.
* Individuals may choose from a number of options regarding the manner in which their budget will be managed, including requesting the local council to arrange their support package, establishing an Individual Service Fund where the budget is held in account, to self-commissioning of services via options such as direct payments.
* Resource Allocation Systems (RAS) vary across local councils but typically apply either the Association of Directors of Adult Social Services (ADASS) or In Control model; in fact, the ADASS model emanates from In Control.
* Evaluative data of the cost of personal budgets is described as 'patchy' but some small scale studies report reductions in the cost of support packages of approximately 10%. The studies note that the mere introduction of a new scheme is likely to identify unmet need and consequently, increase demand.
* The impact of transitioning to self-directed services for specialist disability providers has been pervasive.
* Clear descriptors of support options, with respective costs, are now required by budget holders as they develop support plans.
* New services have emerged including advocacy, brokerage and information services.
* Issues of governance, regulation, and the impact of self-direction on employees are currently under consideration.
* Investment in pilot initiatives such as Right to Control continue to refine the new system of personalised supports.

**USA Experience:**

* Community-based disability services throughout the US are largely funded by federal and state-matched funding under the Medicaid Home and Community Based Services (HCBS) Waiver Program.
* Increasing demand for disability services, at a time of budgetary shortfalls, is placing pressure on states to use their funding in more efficient and equitable ways.
* Consumer-directed services have a long tradition throughout the US, being pioneered initially by advocates and more recently being made available across all Medicaid HCBS programmes.
* Individual budgets are a core element of consumer-directed programs. States vary in the methodologies they employ to determine individual budgets but are federally obliged to ensure that the method is data-based and used consistently across the state.
* Common methodologies to calculate individual budgets include the use of historical cost and service utilisation data or the use of more sophisticated mathematical formula models.
* Mathematical formula models may derive Individual-based Budget Allocations (IBAs), where each individual is allocated a unique budget, or Level-based Budget Allocations (LBAs), where individuals are assigned to a level of allocation, albeit with finer distinctions within each level.
* The DOORS project in Wyoming and ReBar project in Oregon provide useful examples of IBA and LBA models.
* State licensed or certified disability providers are federally obliged to employ standard reimbursement rates for services. These rates must be transparent to potential service users and must be itemised in considerable detail for billing purposes. Bills are typically paid by a brokerage service to the provider on instruction from the budget holder.
* Federal requirements for data-based methods to determine individual budgets have led many states to use standardised and psychometrically tested measures of support need.
* A comprehensive comparison of a number of support need assessments found that the Supports Intensity Scale (SIS) was the most robust. The SIS has widespread use both within the US and internationally.
* While traditionally available to those with developmental disabilities within the US, there is legal scope to expand consumer-directed options to others, in particular, to those with mental health difficulties and to veterans, both of whom have expressed interest in this model of service delivery.

**Allocating Resources on the Basis of Individual Support Needs:**

* The benefits of introducing a system-wide resource allocation model based on individual support need are multiple. From an equity perspective, people with most need receive the most support. From an enabling perspective, budget holders exercise control over their support and can change their provider secure in the knowledge that the ‘money follows the person’. From a transparency perspective, the format of standardised assessments of support need and the cost of service options should be clearly communicated and publicly available. From a cost perspective, savings of 10% and higher have been achieved where individual budgets have been introduced. Ultimately, any chosen resource allocation system should deliver quality outcomes not only for individuals but also for their families; the evidence suggests that individual funding models are associated with such quality outcomes.
* The Support Model represents a substantial paradigm shift within the disability field, moving to a focus on the individualised supports a person requires to achieve a particular lifestyle outcome, rather than a traditional focus on any perceived limitations a person may experience due to disability. The impact of the supports paradigm has substantially altered professional practices within the disabilities field, where assessment of support need has become a basis for individualised planning and resource allocation.
* The American Association on Intellectual and Developmental Disabilities (AAIDD) has developed a support model which outlines the various steps required to develop an individualised service based on support need; the steps include personal centred planning, assessing support need, developing an individual support plan, and finally, ongoing monitoring and evaluation of the plan to ensure personal outcomes are achieved.
* Individualised funding is defined as 'resources that are allocated based on needs which are identified through the planning process, to support the design and identification of supports that are flexible and responsive to individual need'.
* Individual funding models may be classified as retrospective or prospective. Retrospective models calculate the person's allocation during the person centred planning and support planning process. In contrast, prospective models determine the person's allocation prior to the development of their plan. Prospective models are favoured in the UK and US.
* The selection of appropriate support needs assessment tools is a key consideration in the development of a resource allocation system based on individual support need. Three measures were selected for review in this document: the In Control RAS 5, the AAIDD Supports Intensity Scale (SIS) and the Centre for Disability Studies, University of Sydney's Instrument for the Classification and Assessment of Support Need (I-CAN).
* Each measure was briefly reviewed and assessed against four criteria: whether it has been used within the context of determining individual budgets, whether it was developed for use at national as opposed to local level, whether it has demonstrated robust psychometrics, and whether it is appropriate for use across a range of persons with disabilities.
* In Control's system of self-directed support is credited with introducing the concept of personal budgets within the UK social care system. It is now in widespread use throughout local councils in England and is being introduced in a number of jurisdictions internationally.
* The In Control resource allocation system, RAS 5 (reflecting that it is now in its fifth iteration) is based on a self-assessment questionnaire (SAQ) of support need. Each SAQ item is allocated a 'point per price' cost which is determined locally by each council. The system is endorsed by the Association of Directors of Adult Social Services (ADASS) as a template RAS for their national Common Resource Allocation Framework.
* The RAS provides an indicative allocation which is finalised when the person's support plan is agreed. Self-directed support, as promoted by In Control, emphasises the personal outcomes individuals achieve rather than the determination of funding they receive.
* In Control's RAS 5 may be deemed to reach three of the four criteria set out above: it has been used extensively within the context of determining individual budgets, it has been used nationally, and it has been used across a wide range of persons with disabilities. It does not, however, have the weight of psychometric analyses that other tools have. This does not necessarily mean the data are not available, or sufficiently robust, for such analyses but does mitigate against a comprehensive evaluation of the tool.
* The Supports Intensity Scale (SIS) was developed over a five year period by the AAIDD for use by disability organisations working with persons with intellectual and developmental disabilities. The SIS comes with an extensive psychometric pedigree having been standardised on a large US sample. The SIS is used widely both in the US, currently in 14 states, and internationally, in 19 countries. It has been psychometrically tested in three foreign languages.
* In addition to its function as a support needs assessment, the SIS is widely used for resource allocation and service payment calculations. The Human Services Research Institute (HSRI) has considerable experience in implementing the SIS as a resource allocation system in a variety of jurisdictions. Administration of the scale requires extensive training by AAIDD to ensure the fidelity of the measure. Combined with financial data, the measure is commonly used to allocate individuals to funding levels, each with discrete funding ranges, based on individualised support need.
* The SIS may be deemed to reach three of the four criteria set out above: it has been used extensively within the context of determining individual budgets, it has been used nationally, and it has scientifically robust psychometric qualities. It has not, however, been extensively trialled with persons with a range of disabilities, but rather has been implemented for those with intellectual and developmental disabilities. The suitability of the scale items, and the normative data, may need to be reviewed to determine their suitability for use with persons with other disabilities, such as physical or sensory disability or those with mental health difficulties.
* The I-CAN (Instrument for the Classification and Assessment of Support Need) has been under development since the late 1990s by the Centre for Disability Studies, University of Sydney. Based on the theoretical frameworks of AAIDD and WHO's models of disability, the measure focuses on the interaction between individuals and their environments via an array of supports.
* Version 4 of the I-CAN utilises an ICT platform, essentially enabling assessments to be conducted online. The software allows for the collection of both qualitative and quantitative data and produces a wide range of reporting facilities. Financial data are captured by apportioning salary and related costs of an individual's service.
* I-CAN reaches three of the four review criteria; it has potential for use at national, as opposed to local level, it has been psychometrically tested, and it has application for persons with a range of disabilities. It has not, however, the level of implementation in the realm of determining individual budgets that has been observed for the tools previously reviewed.
* Attempts to compare the three support needs assessment tools, in terms of the key domains covered by each, proved challenging. The contribution of each domain within a resource allocation could not be determined for two of the tools and as such the comparison was limited to observation of the domains. All cover key areas such as employment, safety, personal care, physical and mental health, social relationships and community engagement.
* Attempts to compare the three support needs assessment tools on psychometric data were restricted to a comparison of the SIS and I-CAN, as In Control’s RAS5 does not have published psychometric data. Findings revealed that both measures were extensively tested, with the I-CAN reporting greater consistency in results across different administrators, and the SIS reporting greater consistency when administered over different time periods.
* A final comparison outlined the performance of each assessment tool on the four criteria set out above. The findings revealed that while each endorsed three of the four criteria, not one achieved success across all four. This does not mean that the measures do not have the capacity to reach the outstanding criteria, but rather that the current evidence base would not allow for a final determination. The choice of any of these measures for application in Ireland may rest with the prioritisation of each criterion. Other things being equal, which is of greater importance, that the assessment tool be standard across all persons with disabilities, that it is psychometrically robust, or that it has been used elsewhere, successfully, as a resource allocation tool?

**Implementing a Resource Allocation Model based on Individual Support Need in Ireland:**

* The proposed introduction of a resource allocation model based on individual support need in Ireland is timely. Recent reviews of the disability sector and the funding of health services, combined with the introduction of new negotiation agreements with disability providers have set an expectation of change.
* The market for disability support services is likely to change markedly with the introduction of self-direction and individual budgets. These changes must be linked with a system of registration and standards to ensure that funding is linked to standards. This is to ensure that only those services which reach an acceptable standard can be funded, and to avoid competition resulting in a ‘race to the bottom’. A system of registration linked to standards can also ensure that new entrants may join the market.
* Greater financial transparency would be required of disability providers to ensure that people with disabilities, who would now be offered the opportunity to manage the budget for their supports, can make an informed choice when selecting disability support services.
* The robust resource allocation systems reviewed in this report deal in the main with social care services for adults. While both In Control and the SIS are currently developing tools for application with children, the effectiveness of these tools and the application to health services such as therapeutic services and other medical supports requires further exploration. In addition, the alignment of such tools with the statutory needs assessment process under the Disability Act requires in-depth investigation.
* Ireland has 'late mover advantage' and can learn from the experiences in other jurisdictions where resource allocation models based on support need have been implemented. While there are undoubtedly cultural differences, the experiences of others can assist in raising issues for consideration, and possibly pre-empting mistakes made elsewhere.

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| Key Considerations for Resource Allocation Models in an Irish Context | | |
|  | Strengths | Issues for Consideration |
| In Control’s RAS5 | Developed for use in social care systems but flexible enough to extend to other areas such as health care needs.  Used extensively to allocate resources across people with a range of disabilities.  In Control template has been modified in England to appreciate local configuration of available resources.  Version for application to children is in early stages. | Psychometric data are not publicly available to confirm the reliability and validity of the In-Control RAS 5 as a support measure, or to determine its predictive power in determining costs.  With the focus on resource allocation for social care services it is not clear how this tool would align with Ireland’s needs assessment process under the Disability Act. |
| SIS | A comprehensive comparison of support needs measures identified the SIS as the most robust.  Has widespread use both within the US and internationally.  Its predictive power to determine costs associated with supports for persons with intellectual disability has been established.  Version for children is under development currently. | It is primarily a tool for determining support needs and resource allocations for people with intellectual disabilities.  As a standardised tool, the SIS cannot be modified to accommodate Irish context.  The SIS is a copyright tool and would incur an ongoing cost.  With the focus on resource allocation for social care services it is not clear how this tool would align with Ireland’s needs assessment process under the Disability Act. |
| I-CAN | Its use as a support needs measure, across a range of people with disabilities, is enhanced by the development of an online version which enables administrators to generate template reports. | Has limited use within the context of determining individual budgets.  I-CAN is a copyright tool and would incur an ongoing cost. |

# 1. Disability Services in Ireland

According to the National Disability Survey[[3]](#footnote-3), an estimated 218,000 individuals in Ireland have a significant disability as defined by self-reporting 'a lot' or 'total' difficulty carrying out everyday tasks. Only a minority of these individuals, approximately 56,000 are identified as being in receipt of, or awaiting, specialist disability services[[4]](#footnote-4). These specialist services cover a range of supports for people with disabilities across the lifespan including early childhood and family support services, community-based medical, nursing and therapy services, aids and appliances, home-based supports, day services, specialist services for persons with autism spectrum disorder and acquired brain injury, rehabilitative training, sheltered work, employment services, respite services, residential services, financial allowances and miscellaneous support services such as information and advocacy[[5]](#footnote-5).

The disparity in the numbers of persons self-reporting a significant disability, when compared with those receiving specialist disability services suggests that the majority of people with disabilities are availing of mainstream services and/or natural supports such as family or friends to meet their needs[[6]](#footnote-6). The use of mainstream services is supported by Irish disability policy. Initiatives such as the Housing Strategy for People with Disabilities and the Comprehensive Employment Strategy for People with Disabilities aim to promote provision to people with disabilities through mainstream services.

Alongside the promotion of mainstream service delivery are a number of developments examining the current delivery of specialist disability services. Comprehensive reviews of the status of congregated residential settings and of adult day services for people with disabilities are now complete. These reviews, while not yet approved at Ministerial level, have generated an expectation by disability groups of radical change within disability services in Ireland[[7]](#footnote-7). By far the most influential review currently being undertaken is the Review of the Efficiency and Effectiveness of Disability Services in Ireland. The objectives of the Value for Money Review are to carry out an examination of disability services wholly or partly funded by the State, and to consider whether current policies are consistent with the delivery of objectives of future disability services[[8]](#footnote-8). Specifically, the Department of Health and Children has commented that the review will include a consideration of 'alternative models of funding and budgets for services to enable people with a disability to participate in the social and economic life of their community'[[9]](#footnote-9).

## 1.1 The Funding of Specialist Disability Services in Ireland

The responsibility to provide health and personal social services in Ireland is delegated from the Department of Health & Children to the Health Service Executive (HSE)[[10]](#footnote-10). The type and volume of these services provided by HSE are outlined annually via a National Service Plan[[11]](#footnote-11). The 2010 National Service Plan identified the HSE budget for health and personal social services delivered specifically to children and adults with disabilities at €1.467 billion. These disability specific services are delivered either directly by HSE or, in the case of the majority of services, in partnership with non-statutory voluntary service providers. The disability budget is disbursed by HSE to the 32 HSE Local Health Offices (LHO) nationwide, or directly to some of the larger non-statutory voluntary service providers at regional level[[12]](#footnote-12).

In 2010, the budget for disability services delivered directly by HSE amounted to €450 million, while the budget for services delivered via non-statutory voluntary bodies was €1.026 billion[[13]](#footnote-13). The breakdown of the Revised Estimates for the 2010 disability budget indicates that the majority of this funding, €858 million, is allocated to intellectual disability and autism spectrum disorder services, €551 million is allocated to physical and sensory disability services, €56 million is allocated to 'other' services and €10 million is allocated to allowances[[14]](#footnote-14).

Approximately three quarters of the entire disability expenditure in 2009 was spent in two key areas, residential supports (48%) and adult day care services (26%). The remaining expenditure covered allowances, multidisciplinary teams, early intervention teams, personal assistant services, respite, transfer from inappropriate placements, aids and appliances, and other rehabilitative services[[15]](#footnote-15). This distribution of expenditure reveals how many items of expenditure within the disability budget, as financed by the Department of Health and Children, do not constitute 'health care as defined in other countries'[[16]](#footnote-16).

The quantum of disability specific services to be delivered annually, as outlined in the National Service Plan, is currently guided by two national databases, the National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database (NPSDD)[[17]](#footnote-17). These databases detail the existing level of specialised health and personal social service provision and provide an assessment of need for the upcoming five year period[[18]](#footnote-18). The voluntary nature of the enrolment of individuals on these databases combined with the absence of a standardised approach to needs assessment has led the Comptroller and Auditor General to question the appropriateness of the databases for service planning[[19]](#footnote-19). The National Disability Authority (NDA) has also raised concerns as to whether the voluntary nature of the databases allows for a complete picture of service delivery or aggregate need for disability services. The NDA also questions the concentration of the databases on those aged 66 years and younger, given that the incidence of disability is known to increase markedly with age[[20]](#footnote-20). These concerns raise serious questions as to the suitability of the databases for planning disability services and have resulted in calls for the integration of these databases with other disability databases held by HSE[[21]](#footnote-21) in an attempt to improve the comprehensiveness and coverage of the data.

## 1.2 Funding of Non-Statutory providers under the Health Act 2004

Legislative provision for the funding of non-statutory disability organisations is set out in Sections 38 and 39 of the Health Act 2004. Section 38 grants[[22]](#footnote-22) apply to organisations providing services on behalf of the HSE[[23]](#footnote-23). Section 38 funding is currently limited to 26 organisations within the HSE Employment Control Framework[[24]](#footnote-24). Section 39 grants[[25]](#footnote-25) apply to organisations that provide a service similar, or ancillary to, a service that the HSE may provide. While theoretically the distinguishing factor between Section 38 and Section 39 funded organisations is that the former provides services 'on behalf of' the HSE and the latter provides services 'with the assistance of' the HSE, commentators have noted that there is, in fact, little to distinguish the types of services provided by some organisations in receipt of Section 38 and Section 39 grants[[26]](#footnote-26).

Essentially both Section 38 and Section 39 provider organisations can be contracted by HSE, without a tendering process, as a provider of disability services within a specific geographical area in arrangements that have been described as 'contracts of indefinite length'[[27]](#footnote-27). This type of contract is typically being replaced in other international jurisdictions by options such as block grants that are linked to standard unit prices, commissioning involving open competitive tendering or the identification of preferred providers[[28]](#footnote-28) or individualised funding models based on standardised assessments of need[[29]](#footnote-29). These alternative models of funding provide greater opportunities for new entrants to the market, and provide people with disabilities greater flexibility in selecting a provider[[30]](#footnote-30).

Capital costs of Section 38 and Section 39 organisations are eligible for funding under the HSE Capital Programme, which is negotiated as required on an ad-hoc basis. In contrast, the negotiation of non-capital costs are currently in a period of transition. To 2009, these costs were regulated annually via Service Level Agreements. These agreements have come under scrutiny for the heterogeneous nature with which they are applied across organisations, for their weak link between service delivery and funding, and for their failure to allow for the calculation of units costs for each type of service being delivered[[31]](#footnote-31).

In light of these criticisms, negotiations between HSE and provider organisations are now transferring to regulation via new Service Arrangements. The Service Arrangements comprise two parts, firstly a standard set of terms and conditions and secondly, a suite of ten schedules that are agreed annually between HSE and service providers. A National Register system has been introduced to monitor the completion of all Service Arrangements[[32]](#footnote-32). The suite of schedules will require organisations to furnish an array of information annually to HSE including contact details, level of funding and quantum of service, performance monitoring arrangements, quality and standards to which the service must be provided, personnel numbers, insurance and complaint arrangements[[33]](#footnote-33),[[34]](#footnote-34).

Detailed non-capital costs are captured under Schedule 3 (Service Delivery Specification) of the new Service Arrangement. The National Business Support Unit of the HSE has now developed a number of templates to standardise the submission of Schedule 3 data from provider organisations. Available templates include a Minimum Data Set template[[35]](#footnote-35) which gathers detailed non-capital cost data at the level of service units, a generic resource allocation model template which gathers more detailed information, and a Disability Review 2010 template specifically developed to gather data for the Review of Disability Services under the Value for Money and Policy Review Initiative 2008-2011. The National Business Support Unit is currently in the process of obtaining first returns of non-capital costs for the financial year 2009 using a combination of the Disability Review 2010 template and the Minimum Data Set template[[36]](#footnote-36).

While the detailed financial information gathered from Service Arrangements will provide greater clarity regarding the quantum and costs of disability services in Ireland than the Service Level Agreements they replace, the exclusion of data regarding service needs and costs at the level of the individual is noted as a missed opportunity[[37]](#footnote-37).

## 1.3 From Incremental Determination Processes of Funding to Individual Budgets

To date, Service Level Agreements have been negotiated between service providers and their Local Health Office area or directly with their HSE regional area (Dublin Mid Leinster, Dublin North East, West, or South). Aggregated estimates of non-capital costs identified in the Service Level Agreement were used by HSE to determine an annual block allocation for the service provider. This allocation was devolved throughout the provider organisation to the level of units and centres, but not to the level of individuals. Block funding allocated in this manner follows an 'incremental determination process', that is, a process whereby previous annual funding is used to estimate the required funding for the same level of service to be provided in the upcoming year[[38]](#footnote-38). Fundamental to this process is the first budget upon which subsequent funding is based. In the case of more established service providers in Ireland, this baseline year may hail from previous decades[[39]](#footnote-39) and consequentially the original rationale for the allocation may no longer be transparent.

The HSE acknowledge that due to the historical manner in which incremental determination processes have allocated funding in Ireland, standard unit costs for services are not available nationally. As such, there is no 'average' national cost per service place other than estimates derived to guide one-off initiatives such as the multi-annual investment programme (MAIP), a three year programme targeted at developing specific disability programmes. While the identification of a ballpark cost, such as an average €80,000 cost per residential place, was sufficient for MAIP purposes, these average costs are determined on the basis of available funding and do not take into consideration the individual support needs of those in receipt of the service[[40]](#footnote-40). A similar bias may arise with the financial data gathered via the Schedule 3 templates whereby any attempt to determine unit costs from these data will be based on historical legacies of staffing levels and not on individual support need.

An extensive review of the provision of disability services by the non-statutory sector, conducted by the Comptroller and Auditor General in 2005, expressed concern about the use of incremental determination processes to allocate disability funding in Ireland. The report noted that the risk of such an approach is that, over time, core funding becomes weakly linked with levels of need. Indeed, per capita allocations for disability services in Ireland have been found to vary considerably by geographical region and by service provider[[41]](#footnote-41),[[42]](#footnote-42). This failure to reflect true differences in service need, combined with a historical method of allocating resources has been criticised as a system of allocation that 'perpetuates existing inequalities'[[43]](#footnote-43).

In 2010, the Report of the Comptroller and Auditor General and Appropriation Accounts[[44]](#footnote-44) reported that despite their previous caution in 2005 regarding the reliance on this model of funding[[45]](#footnote-45), there had been no substantial change in the HSE's approach to resource allocation. Annual allocations continued to be made by reference to historical levels of funding, adjusted for new service developments and regrettably did not gather information regarding the support needs of individuals. Moreover, the National Disability Authority note that the sporadic nature of completion of the new Service Agreements is causing difficulty in ascertaining 'what services are being provided, to whom, with what personnel resources, at what cost'[[46]](#footnote-46).

This dissatisfaction with current funding structures contributes to a growing call for radical change to the manner by which disability support services are funded in Ireland. The changes that are being called for are well reflected by the findings from a recent public consultation undertaken by the Office of Disability and Mental Health as part of the Value for Money & Policy Review of Disability Services. The report concludes with a proposal to reframe disability services towards a model of individualised supports where state funding would be allocated on the basis of individualised support needs. Individuals would be offered the option of receiving a budget in the form of a direct payment from which they can purchase services directly, or in the form of a brokerage system whereby the individual has choice and control over how the budget is spent, but a broker is responsible for managing the budget and commissioning services[[47]](#footnote-47).

Provider organisations themselves are also critical of the historical manner in which services are funded, commenting that block funding is a major obstacle to the implementation of person-centred approaches to disability support[[48]](#footnote-48). Some have attempted to 'unbundle' block grants to deliver personalised support arrangements for their service users[[49]](#footnote-49). Also, a number of umbrella organisations of providers, family members and advocates have been established such as 'New Options Alliance' and 'Taking Control'[[50]](#footnote-50) with the specific aim of promoting new and innovative practices including individual budgets. Most notably, consultation with people with disabilities themselves reveal that while some concerns exist regarding the sufficiency of supports required by individuals to manage their own budget, the overall policy of moving towards individualised funding is positively received by people with disabilities[[51]](#footnote-51).

## 1.4 Proposals for Resource Allocation in the Irish Health Sector

Any proposed movement towards the introduction of an individually based resource allocation model for persons with disabilities in Ireland should take cognisance of two reports issued in 2010, both of which have called for substantial changes to the allocation of funding resources within the Irish health sector. The Staines Report[[52]](#footnote-52) addressed the issue of how the nationwide budget for Primary, Continuing and Community Care areas (PCCC) could best be allocated in proportion to the need for services within these areas. Following an examination of the allocation of resources from HSE to the 32 Local Health Offices (LHO) nationwide in 2007, the report concludes 'at present it is difficult to ascertain exactly how resources are allocated between care groups at LHO level. Budgets do not reflect service provision to the population at LHO level, and there is no real systematic approach to resource allocation'[[53]](#footnote-53). The study recommended the introduction of a new resource allocation model which would operate at LHO level using proxy age and gender-specific estimates of health service usage within these geographical regions.

Specifically addressing the allocation of funding to disability services, which in 2007 comprised the largest recipient by service type of the entire PCCC budget at 19.6%[[54]](#footnote-54), the Staines Report highlighted how just over half of the disability specific budget (55%) was allocated by HSE to the 32 LHO areas nationwide. The remaining expenditure of the disability budget, at 45%, was not funded via the typical LHO route, but rather was funded directly by HSE to some of the larger non-statutory voluntary service providers. The report notes that this pattern of allocation would need to be addressed if proposals to allocate resources via LHO level proceed. The authors conclude 'any effective resource allocation system will have to ensure budgetary stability for these providers' (p.68).

The second report of relevance to the issue of resource allocation in Ireland is the Report of the Expert Group on Resource Allocation and Financing in the Health Sector[[55]](#footnote-55). The Expert Group was charged at the request of the Minister for Health and Children with examining how the existing system of resource allocation across the entire Irish health sector could be improved to deliver better, and more equitable health care provision[[56]](#footnote-56). As a starting point, the Expert Group established a set of guiding principles based on common characteristics of 'good' resource allocation systems in other jurisdictions[[57]](#footnote-57), the majority of which have moved from block funding to allocations based on the casemix of patients within the acute health sector[[58]](#footnote-58),[[59]](#footnote-59). Using these principles, the Expert Group outlined a series of 32 detailed recommendations to guide the development of a resource allocation model for the Irish health care sector. Among these recommendations are a call for the immediate development of a resource allocation model to underpin a five year planning cycle that systematically distributes funding using predictors of health such as age and social deprivation nationwide. The report calls for a clear division between purchaser and provider functions, with reimbursement to provider organisations being subject to the attainment of quality standards using nationally-agreed care protocols, contracts devised by HSE and a common set of reference prices for services. The Expert Group noted that Ireland has a 'late mover advantage' in that much of this work has been completed in other countries where valuable lessons can be learned[[60]](#footnote-60). The Expert Group called for the establishment of an implementation body of experienced and independent experts for the implementation of the new resource allocation model in Ireland.

With specific reference to community and continuing care programmes, the Expert Group noted that disability services comprise the largest expenditure within these programmes and that international trends in disability service provision are moving away from a medical model of care towards a social model that emphasises self-determination. As these services move towards community based settings, the Expert Group proposed that local level HSE personnel will have a 'major role' in co-ordinating care provision, albeit a development that will take 'some time to complete, as it has done in other countries'[[61]](#footnote-61). The introduction of individualised funding options within the community and continuing care sector was supported by the Expert Group who called for further potential for more individualised solutions[[62]](#footnote-62).

Regarding the optimum level at which funding should be devolved nationally from HSE to meet population need, the Expert Group proposed the new Integrated Service Areas (ISA)[[63]](#footnote-63). ISA regions are a central element of the new HSE Integrated Care Model of health care delivery. To date, eight such ISAs have been defined nationally with others under discussion. While ISA regions will cover a larger proportion of the population than the LHO areas recommended for resource allocation by the Staines Report, both proposals aim to meet the same objective; to allocate funding locally based on population need. The challenge of both proposals is how to incorporate the funding of larger non-statutory voluntary providers that is currently allocated directly via HSE and not regionally as per the current LHO allocations. The Expert Group note that in 2009, €458.4 million was allocated to non-statutory disability providers using this system of allocation[[64]](#footnote-64),[[65]](#footnote-65).

In combination, both the Staines report and the Expert Group on Resource Allocation report outline proposals for the restructuring of resource allocation within the broader health sector in Ireland. The new resource allocation model should be based on estimated need within regional areas, promote individual care solutions, and provide transparency and equity in access to services[[66]](#footnote-66). Clearly, any developments regarding the restructuring of resource allocation in disability services should be undertaken cognisant of, and in conjunction with, the proposed implementation of a new resource allocation system within the broader health context.

## 1.5 The Assessment of Need for People with Disabilities in Ireland

By definition, in order to provide an appropriate allocation of funding to adequately meet an individual's need for support, an assessment of those support needs is required. Part 2 of the Disability Act 2005[[67]](#footnote-67) provides for the assessment of need for individuals who believe they have a disability[[68]](#footnote-68), without regard to the cost or capacity to provide services identified in the assessment. Any introduction of individualised funding for people with disabilities based on support need is likely to sit within the framework of the current Assessment of Need legislation and practice.

The Assessment of Need process commenced in June 2007 for children under five years and is regulated by a set of standards devised by the Health Information and Quality Authority (HIQA)[[69]](#footnote-69). Under Part 2 of the Act, children with disabilities have a right to an independent assessment and annual review of their health and educational needs arising from their disability. Applicants are entitled to an Assessment Report which should outline whether the applicant has a disability; the nature and extent of the disability; a statement of the health and educational[[70]](#footnote-70) (if any) needs arising from the disability; the appropriate services required to meet the needs of the applicant and the time ideally required to deliver those services; and the timeframe within which such services should be provided.

Where an Assessment Report is furnished to the HSE which includes a determination that health and/or educational services are appropriate for the applicant, a Service Statement is prepared within one month setting out the health and educational services which will be provided and identifying the time period within which these services will be made available. Preparation of a Service Statement must have regard for 'the need to ensure that the provision of the service would not result in any expenditure in excess of the amount allocated to implement the service plan of the Executive [HSE] for the relevant financial year'[[71]](#footnote-71). A review of the Assessment Report should be undertaken on an annual basis. Applicants who are dissatisfied with aspects of their application have recourse to redress via the Office of the Disability Appeals Officer[[72]](#footnote-72).

The HSE is required to maintain records of the assessments being conducted for the annual publication of, among other data, the aggregate need identified in the assessments, that is, by those who have not received a service cited within their Service Statement. Details are required of the timeframe within which these services will be provided alongside an estimate of the cost of provision.

The Department of Health and Children acknowledge challenges in the implementation of Part 2 of the Disability Act. These challenges include the difficulty of making determinations of disability on young children and of providing comprehensive Assessments of Need within the specific timeframes required by the legislation[[73]](#footnote-73). The HSE report that the number of assessments completed within the specified statutory timeframe 'remains low in overall terms' and varies widely in different LHO areas[[74]](#footnote-74). Parents have identified gaps in the provision of supports identified in Service Statements[[75]](#footnote-75), while health professionals working within the assessment system have highlighted how the Assessment of Need process has impacted on the work practice of early intervention teams, with more time being spent on assessment and less on intervention than prior to the introduction of the system[[76]](#footnote-76). The Department also acknowledge that while it had been the intention to have the Disability Act 2005 and the Education for Persons with Special Educational Needs Act (EPSEN) 2004 fully implemented in respect of children between 5 and 18 years of age by 2010, substantial resources would have been required to prepare both education and health sectors for this implementation. The Minister has thus far only commenced Part 2 of the Disability Act for children aged 0-5 years and there is no indication as to when this will be extended to others or when EPSEN will be implemented, due to the financial circumstances[[77]](#footnote-77).

Further challenges are acknowledged by HSE who are charged with producing an annual publication on the Assessment of Need process. Difficulties in quantifying levels of unmet need resulted in a one year delay in the publication of 2008 Assessment of Need data. As a consequence HSE published both 2008 and 2009 data under one report issued in 2010. This report reveals that 2,535 applications for Assessment of Need were received in 2008, with a further 2,525 applications in 2009. The report also illustrates the considerable resources required by clinicians to undertake these assessments. The report estimates that the number of clinicians required to meet the demand of assessments by 2012 will be in the region of 182 therapists whose sole focus would be the completion of these assessments. This estimate reflects the highly clinical nature of the assessments of needs being undertaken to date. The report estimates that multidisciplinary teams of clinicians are spending an average of 26 hours clinical input on each assessment.

A diversion of clinical work may be more likely to arise among Early Intervention Teams where the Assessment of Need process is recommended as the 'single point of entry' for service delivery. There are, however, Early Intervention Teams that operate a dual system of assessment, whereby some children are referred through the Assessment of Need process while others take more traditional routes such as referral by an Area Medical Officer or a Public Health Nurse[[78]](#footnote-78). The latter option, which is not confined by the time constraints within which statutory assessments of need must be completed, is likely by definition to afford clinicians more flexible opportunities to complete assessments within the broader context of their clinical work.

Recognising the challenges in how the needs assessment process is implemented, efforts are underway to address these.

## 1.6 The Role of the Assessment of Need process in determining Individual Budgets

Notwithstanding the difficulties currently being experienced in the implementation of the Assessment of Need process, the rights conferred by Part 2 of the Disability Act and the establishment of an infrastructure within the 32 Local Health Offices to coordinate these assessments are fundamental to the development of a resource allocation system based on individual support need. Part 2 entitles individuals to an independent assessment of their health and education needs, and although 'health needs' per se are not defined, 'health services' are defined by the act as 'including a personal social service'[[79]](#footnote-79). The inclusion of supports for 'personal social services' is an important caveat in the potential role of the Assessment of Need system in determining individual budgets. International trends in the development of individual budgets typically focus on the use of personal social services funding as a mechanism for individuals to have greater control and choice over their own supports[[80]](#footnote-80). In jurisdictions where individual budgets are available to individuals with disabilities, it is the budget for direct care support that is typically allocated to individuals, as health supports are provided through mainstream services. Using this model, clinical assessments, such as those currently undertaken within the Assessment of Need process may be more appropriately undertaken within the context of clinicians' ongoing intervention work, while more holistic assessments could be undertaken to determine an individual's overall support needs.

One advantage of moving towards a more holistic assessment is that it would provide an opportunity to promote the use of a standard assessment tool. Current practice is that different clinicians and different multidisciplinary teams may use different assessment tools. As a consequence, individuals in similar circumstances may receive a different assessment of need and consequently be offered a different type of service[[81]](#footnote-81). A standard tool used as part of a resource allocation process would contribute to a reduction in inequities of this nature.

Currently, an infrastructural framework exists, albeit limited to children, for the coordination of assessments of need within each of the 32 Local Health Offices (LHO). Assessment Officers and Liaison Officers have been appointed within each LHO to support applicants through the assessment process[[82]](#footnote-82). The challenges of implementing a highly clinical assessment, as is currently being experienced nationwide, may provide an opportunity for consideration of more holistic assessments of need, focusing less on an individual's requirements for clinical supports, and more on an individual's overall support needs in terms of both health and personal social services. Given that almost three quarters of the expenditure for disability specialist services is used to fund residential supports and adult day care services[[83]](#footnote-83), a broader focus on the assessment of health and personal social services for adults with disabilities may be more appropriate. Such an assessment would consider the level of support that an individual with a disability requires to live as independently as possible.

An IT infrastructural framework also exists to support the assessment of need process in the form of a database currently managed by the HSE's Disability Information Unit, the Assessment Officers' System (AOS) Database. The Department of Health and Children and the HSE are currently in discussion regarding the sharing of information between this database and three other disability databases; the Rehabilitative Training Database hosted by HSE, and the NIDD and NPSDD hosted by the Health Research Board[[84]](#footnote-84). The integration of these databases could provide a more comprehensive portrait of those requiring disability support services nationwide and address some of the concerns previously cited regarding the appropriateness of the NIDD and NPSDD for planning and costing disability services. Certainly, the inclusion of Assessment of Need data as the system rolls out across different age groups, would provide a mechanism for including individual support need data within the planning process.

Finally, a distinct advantage of using the Assessment of Need infrastructure as a framework for the implementation of support needs assessments is the independence this structure affords. Clearly, there may be a conflict of interest where those who are responsible for determining assessments of need, and subsequently determining an individual budget based on those needs, are the same persons who may be a beneficiary of the budget if they are providers of disability support services.

## 1.7 Reframing Disability Service Provision in Ireland

The call for a move towards individualised supports for people with disabilities in Ireland is gathering momentum. Recent initial findings from the Review of Disability Services[[85]](#footnote-85) call for a reframing of the provision of disability services towards a system of individualised supports. Individualised supports are defined as "a personal social service which includes a range of assistance and interventions required to enable the individual to live a fully included life in the community. Individualised supports require the provision of a flexible range of supports and services that are tailored to the needs of the individual, and are primarily determined by the person". The Review proposes that an independent assessment of need will shape an individual support plan for each individual and identify an "individualised budget which is a sum of money that attaches to the person and is used to provide the supports and services they receive".

The implementation of an individualised support system for people with disabilities in Ireland will provide a transparent link between resources and support needs and will provide real opportunities for choice regarding support options. Recall that currently in Ireland per capita allocations for disability services in Ireland vary considerably by geographical region and by service provider[[86]](#footnote-86),[[87]](#footnote-87) a system of allocation that has been identified by the Comptroller and Auditor General as one which 'perpetuates existing inequalities'[[88]](#footnote-88).

Undoubtedly, the move from disability services to individualised supports will impact considerably on those organisations currently providing disability support services, requiring significant redeployment of finances and staff. The subsequent chapters in this report provide an overview of the experiences in other jurisdictions as they continue their transformation of services to individualised services. As the Expert Group on Resource Allocation and Financing in the Health Sector acknowledge, Ireland has 'late mover advantage' in learning from the experiences of others who have travelled further on the road to providing an equitable and empowering support service for people with disabilities.

## 1.8 Ireland: Key summary points

* The current system of funding disability services in Ireland is guided by the National Disability Databases. The role of these (and related) databases in supporting the development of self-directed services should be reviewed.
* Currently, almost three quarters of all disability funding is spent on residential and adult day care services.
* The funding of non-capital costs is conducted via Service Arrangements between disability service providers and the HSE. These new arrangements will provide more detailed information on service uptake and costs than has previously been available.
* Service Arrangements currently apply a traditional incremental determination process of block funding to disability service providers.
* Funding via commissioning, competitive tendering or individualised funding options is not available. Unit costs, where available, are based on historical staffing levels and not on level of support need.
* A number of recent reports by the Comptroller and Auditor General, Office of Disability and Mental Health and the National Disability Authority have called for the implementation of a more equitable individualised system of resource allocation in place of incremental determination processes.
* Recent reports examining resource allocation models across the wider Irish Health Sector call for a system that is based on need, is equitable and promotes individualised care solutions.
* The Assessment of Need process may provide the independent framework required for the development of individualised services and the allocation of individual budgets based on independently assessed need.
* A move from professionally-led clinical assessments to holistic assessments of support needs would reflect international trends.
* Ireland has 'late mover advantage' in implementing individualised support services for people with disabilities and will benefit from collaborations with those who have implemented these systems in other international jurisdictions.

# 2. Implementing the nationwide introduction of personal budgets: Experiences in the UK

## 2.1 Disability Support Funding

Throughout the UK there is a broad system of publicly subsidised supports for people with disabilities. Social care is a central element of this support and is defined as 'the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships'[[89]](#footnote-89). An estimated 1.75 million individuals receive adult social care support in England alone, where approximately 25,000 providers in the public, private and voluntary sectors provide supports to an estimated cost of £19 billion per year[[90]](#footnote-90).

Social care in England is funded to local councils[[91]](#footnote-91) from a variety of sources including central government funds, council tax revenues, and individuals' contributions to their care packages. In order to receive social care supports from their local council, individuals must first be assessed for eligibility using the criteria set out by the UK Government in their 'Fair Access to Care' (FACS) guidelines[[92]](#footnote-92). These guidelines provide for support needs of both individuals and their carers. Fair Access to Care defines four levels of need; 'critical', 'substantial', 'moderate' and 'low', with local councils being given discretion in setting the level at which social care will be provided. While most local councils provide supports for those with 'critical' and 'substantial' needs only[[93]](#footnote-93), some provide support for individuals with lower levels of need[[94]](#footnote-94).

The UK Government has acknowledged that many councils have expressed concern that some individuals who 'ought' to be receiving supports are no longer eligible, despite the evidence that limiting access to eligibility criteria has only a modest and short term effect on expenditure[[95]](#footnote-95). To address this issue, the Government Green Paper entitled 'Shaping the Future of Care Together' calls for a national assessment system whereby individuals throughout England will have the right to have their needs assessed in the same manner, irrespective of location. Individuals will also have a right to know the proportion of their support costs that will be paid for, and this amount will remain stable regardless of where the individual resides in England. As such the assessment will be 'portable' and the funding will 'follow the person'.

An individual's presenting needs are assessed via a community care assessment (CCA) as per the requirements of the NHS and Community Care Act 1990. The purpose of the assessment is to evaluate the individual's presenting needs and explore how those needs impose barriers to the individual's independence and/or well-being[[96]](#footnote-96). Presenting needs for which a local council will provide supports, because they fall within the council's eligibility criteria, are termed 'eligible needs'. An impact assessment of the revised FACS guidance outlines the future direction of eligibility assessments[[97]](#footnote-97). The revised guidance emphasises that decisions as to an individual's eligibility should be undertaken after an assessment has been completed. Essentially this means that everyone who approaches or is referred to a local council with presenting needs is entitled to an assessment of those needs; a situation which is likely to stimulate demand for assessment. The revised guidance also proposes that these assessments should be person-centred, completed in conjunction with carers and should use self-assessment tools. In addition, timescales for the assessment should be flexible to allow time for relationship building and to ensure that support needs are considered over an appropriate length of time. The shift from a professionally-led approach to needs assessment to an approach that empowers individuals and their carers, combined with an emphasis on holistic support needs as opposed to personal care, aims to provide a more streamlined and effective assessment process. The intention is that by investing in high quality first-time assessment and regular reviews, there is a higher chance of devising support plans that are better designed to meet a person's needs, thereby reducing the need for re-assessment. Currently, proposals for a Common Assessment Framework are being considered as a method to coordinate and reduce duplication of assessment conducted by social care and other services[[98]](#footnote-98).

## 2.2 Personalisation of Disability Supports

Once a local council has identified that the presenting individual has an 'eligible need', the council has a duty to offer the individual either direct service provision or to support the individual to self-direct his or her own services[[99]](#footnote-99),[[100]](#footnote-100). While traditionally, social care supports were provided by services offered by local councils to eligible individuals[[101]](#footnote-101), self-directed supports are now strongly endorsed by the UK Government as a method of enabling people with support needs to exercise control in their own lives[[102]](#footnote-102). Putting People First[[103]](#footnote-103), launched in 2007, provided a commitment for reform of adult social care in England by proposing a unique collaboration between central government, local government, service providers, regulators, service users and carers[[104]](#footnote-104). Among many recommendations contained in the document are:

* the introduction of joint strategic assessments between local statutory, voluntary and private sector organisations undertaken via local area agreements;
* the use of commissioning to incentivise and stimulate high quality provision;
* a common assessment process to determine individual support needs using self-assessment;
* the mainstreaming of personal centred planning and self-directed services;
* the promotion of family members and carers as experts;
* and the introduction of 'personal budgets for everyone eligible for publicly funded adult social care support (other than in circumstances where people require emergency access to provision)'.

Local councils are currently in the process of implementing these recommendations. In particular, the introduction of personal budgets, according to Transforming Social Care, is expected to have made significant steps towards reconfiguring adult social care service and to have achieved a target of 30% of recipients using personal budgets by March 2011. While progress differs in each local council, figures in late 2009 estimated that 14,000 individuals from 61 councils held personal budgets, a figure which increased to 93,000 if those with direct payments were included[[105]](#footnote-105). The pace of change is illustrated by more recent figures from a survey conducted in December 2010 which suggests that up to 244,000 individuals with ongoing support needs are in receipt of a personal budget, an estimated one in four of those eligible[[106]](#footnote-106).

## 2.3 Personalised Funding Options

While the terms personal budget, individual budget and direct payment can sometimes be used interchangeably, they are defined below for clarity specifically within the UK context. They comprise the three main funding options offered to individuals in receipt of social care who wish to self-direct their own services[[107]](#footnote-107):

**Personal budget**[[108]](#footnote-108) - an 'upfront' allocation of social care resources based on an assessment of the individual's need for non-residential social care. Following the assessment of need, an 'indicative budget' is calculated; essentially a determination of how much the personal budget might be. A financial assessment is undertaken to determine if the individual is required to contribute to the personal budget. A support plan is then prepared outlining how the personal budget will be used to attain specific outcomes detailed in the support plan. As individuals are informed of their budget prior to developing their support plan, this methodology is classified as a 'prospective' approach to resource allocation. Individuals may ask the local council to arrange all of the support services they need to attain their outcomes, or they may request the personal budget is paid directly to them in the form of a direct payment (defined below) from which they purchase their own supports. Alternatively, they may request a mixture whereby some services are arranged by the local council and the remainder of the personal budget is paid directly to them in the form of a direct payment. Local councils are obliged to inform individuals of any contribution they may be required to make to their personal budget[[109]](#footnote-109).

**Individual budget**[[110]](#footnote-110) - similar to personal budgets, but combine local council social care funding with other funding streams[[111]](#footnote-111). A key aim of the individual budget is to reduce or integrate multiple assessments that are required by differing funding streams. In the UK these funding streams can include social care, integrated community equipment services, Disabled Facilities Grants, housing related funding (entitled Supporting People Grants), Access to Work funding and the Independent Living Fund[[112]](#footnote-112). Recipients may receive a cash payment or may ask their local council to purchase services for them up to the value of the budget. A pilot implementation of 959 persons in receipt of Individual Budgets in 13 local authorities (IBSEN project) revealed that while self-assessment tools were available to determine budgets and support plans, some local councils retained the existing community care assessments for new referrals on the basis that the latter were deemed to be more appropriate for some applicants who required assistance in their completion, provided greater information on carers, included information on risk assessment and upheld the standards of the social workers who completed them. Overall, the pilot concluded that individual budgets were more cost-effective than standard care and support arrangements but reported that attempts to bring together different funding streams were significantly hampered by legislative and administrative challenges[[113]](#footnote-113). Typically, those in receipt of individual budgets reported quality of life gains from the opportunities afforded by controlling their own supports. Those working with recipients did, however, express concerns regarding the issues of safeguarding vulnerable populations[[114]](#footnote-114).

**Direct payments** - defined in the UK as a cash payment equivalent to the value of a social care package[[115]](#footnote-115). Since 2003, every local council has been obliged to offer those who are eligible for services a direct payment as an alternative to providing services directly[[116]](#footnote-116),[[117]](#footnote-117), and in fact, almost all had introduced the option of direct payments before the statutory deadline[[118]](#footnote-118). While the vast majority of people who are assessed as needing social care supports are described as having a right to direct payments, there is no obligation on individuals to accept a direct payment should they prefer their services to be directly arranged by their local council[[119]](#footnote-119). Applicants for direct payments must provide evidence that they are in a position to manage their payments, either directly or with support, and must satisfy the local council that the services they intend to purchase will meet their assessed needs adequately[[120]](#footnote-120). While each local council provides advice on what the payments can and cannot support, the use of direct payments to fund permanent residential accommodation is not permitted[[121]](#footnote-121). Typically direct payments are used to employ support staff directly or to purchase a service from an organisation that provides support services. To date, the take up of direct payments has remained highly variable across different local councils in the UK[[122]](#footnote-122). Rates of take-up in England are more than double those in other parts of the UK, most likely a reflection of better implementation policy[[123]](#footnote-123).

**Current terminology** - the term 'personal budget' is becoming the preferred term in the UK for the allocation of funding individuals receive to manage their own services, whether directly or with the support of a service provider. The UK Department of Health now advises that the term 'individual budget', as it pertains to the UK, is no longer in use and that the appropriate term for funding awarded to eligible individuals is a 'personal budget'. A direct payment is thus defined as one option of receiving a personal budget in the form of a cash payment held directly by the individual. Other options include the allocation being held in an 'account' managed by the local council or by a third party in accordance with the individual's wishes. This option is termed an **Individual Service Fund (ISF)** and is used to support individuals to self-direct without taking on the responsibility of direct budget management[[124]](#footnote-124). Individuals may wish to use a combination of these methods of support payments. It is important to recall that while individuals are allocated a personal budget, they are entitled should they wish to spend this budget in a traditional manner using 'in-house' services and, as such, retain the status quo. For others, however, the possibility exists to employ their own staff and design a bespoke service specifically to meet their needs. Between these two extremes, are those who wish the council to commission some services on their behalf while self-directing others[[125]](#footnote-125).

## 2.4 Developing an Individualised Resource Allocation System

Throughout England, local councils are currently in the process of introducing new Resource Allocation Systems (RAS) with a view to transforming social care supports from the traditional system of professionally-led assessments and offers of support packages paid for and commissioned by local councils, to self-assessment processes leading to indicative budgets and personalised support packages. A key principle in the development of each council's RAS is that it is equitable. Guided by this principle, councils are requested to use only one RAS model across all individuals eligible for support, irrespective of type or level of need[[126]](#footnote-126). The UK Department of Health guidelines to local councils recommend that RAS systems comprise the following components[[127]](#footnote-127):

1. an outcome-based self-assessment/supported-assessment questionnaire[[128]](#footnote-128)
2. a resource allocation calculator (often based on a points system which determines how much money to allocate on the basis of a person's response to each item on the questionnaire)
3. a database of people taking up self-directed support
4. tools to monitor and adjust the funding allocations over time.

The RAS aims to provide a prospective 'indicative allocation' for each individual, that is, a rough estimate of the cost of obtaining supports which is only finalised when the support plan is agreed. The support plan should outline how the individual's needs will be met and the actual cost of meeting those needs. Local councils can exercise discretion in deciding upon the final allocation and are advised to embed a contingency element to each allocation. Contingency levels of between 15%-25% have previously been implemented[[129]](#footnote-129). Some councils have noted that individuals with high support needs may inadvertently skew the resource allocation model. To address this issue, councils may decide to exclude individuals with high support needs (e.g. those with support costs in excess of £60,000) or may impose a 'maximum figure' for the indicative allocation, however concern has been expressed that the latter strategy may be open to legal challenge[[130]](#footnote-130).

In an effort to support local councils to successfully implement their resource allocation system, a number of user-friendly guidelines have been produced. The Association of Directors of Adult Social Services (ADASS), for example, has produced a Common Resource Allocation Framework based on findings from the experiences of 18 local councils implementing their resource allocation models. The Common Resource Allocation Framework comprises principles and policy advice, a template personal needs questionnaire, a questionnaire scoring sheet, a financial framework outlining how indicative budgets can be determined from the completed survey, and a systems map indicating how the components fit into the council's current social care system.

ADASS advise that councils develop their RAS by gathering data from an appropriately sized and representative sample of local individuals. Two types of data are gathered; support needs data obtained from the personal needs questionnaire and resources usage data, that is, the current services received by the participating individuals along with the estimated costs of these resources. Essentially there are two main self-assessment tools in use throughout England to assess support needs; the nationally devised ADASS self-assessment questionnaire and the In Control questionnaire. In fact, the ADASS instrument is based on the In Control assessment and some councils have adopted to use a blend of both measures[[131]](#footnote-131). The self-assessment instrument is short and, given the emphasis on self-assessment, is user-friendly. A template self-assessment questionnaire, available on the In Control website, is attached in Appendix A.

Each item on the questionnaire is linked to an outcome which in turn, is linked to a fee, termed a 'pound per point' calculation. Councils vary in terms of the fee they offer and in terms of whether the fee is standard across all items and across all respondents, whether people with disabilities, older persons etc. Depending on the complexity of the RAS, a questionnaire item can be linked to more than one funding stream which may be incorporated into the resource allocation model or which may serve as a 'red flag' that the individual is eligible for specific funding and may require additional assessments[[132]](#footnote-132).

An allocation table is generated from these data showing scores from 0% to 100% and the indicative allocation for each score. There are a number of methods to determine the relationship between points and the personal budget. In Control's current model, RAS 5, uses a non-linear approach based on percentiles, that is, if 50% of the people in the sample score less than 48 points, and 50% people had social care costs of under £6,000 per year, a person scoring 48 points will be allocated a budget of £6,000 per year. Initially, these costs are determined on the basis of the services individuals are currently using, that is, they are based on the pre-RAS system. Typically, these costs are historical and their relationship to supports needs is low. As individuals take up the option of personal budgets, the historical costs are replaced with costs based on personal budgets. The development of these systems requires ongoing monitoring and amendment to ensure that indicative budgets are sufficient to meet need and reflective of costs incurred[[133]](#footnote-133).

The transformation from historical to personal budgets, however, is not without its challenges. Calibration, the term used to describe the process of deciding the relationship between needs and money, is an undoubted challenge for councils. The UK Department of Health, for example, acknowledge that the relationship between funding and need can be weak. Local councils have found that budgets have been calculated as either too much or too little to meet need but without a consistent pattern emerging that can be addressed. Equally, funding can tend to be allocated to those with the highest support needs to the exclusion of those with lesser needs. Clearly, great sensitivity is required where a person's budget is reduced from current amounts to that determined by RAS[[134]](#footnote-134).

The evidence-base from the experiences of implementing personal budgets in England may be briefly summarised from three key studies; the ongoing evaluation of In Control, the IBSEN Individual Budgets Pilot Study conducted in 2008, and the National Survey of Direct Payments Policy and Practice conducted in 2007[[135]](#footnote-135). Evaluations of the impact on those who have received personal budgets, albeit on a relatively small sample of 196 individuals participating in an early In Control evaluation[[136]](#footnote-136), reported positive or no change in eight areas of life. In particular, participants reported greater levels of overall quality of life, community participation and a sense of choice and control upon receiving their own budget. There was, however, some criticism as to whether the In Control RAS was suitable for the wide range of persons who are in receipt of social care, and whether those who were older persons or persons with higher support needs were differentially disadvantaged by the system[[137]](#footnote-137).

A more recent evaluation by In Control[[138]](#footnote-138) reports findings from evaluations in Richmond and Barnsley councils, again reporting overall satisfaction in key quality of life domains by recipients of personal budgets. The evaluation also illustrates the growth in take up of personal budgets supported by In Control, from an estimated 60 individuals in 2006, to approximately 30,000 in 2009. Of those in receipt of personal budgets, just over half are estimated to be older persons (53%), almost one quarter people with physical disability (23%), just under one fifth people with intellectual disability (18%) and the remainder (6%) people with mental health difficulties. Personal budgets were defined for this monitoring exercise as cases where:

* individuals know how much money they can use for their support
* are able to spend the money in ways and at times that makes sense to them
* know what outcomes must be achieved with the money.

The importance of personal budgets as a key driver in the movement towards self-directed services is acknowledged by the recent inclusion of a new indicator for the National Indicator Set for English Local Authorities and Local Authority Partnerships, which currently comprises approximately 198 indicators monitoring the transformation of local government in England[[139]](#footnote-139). National Indicator NI 130 now ensures that local government reports on 'social care clients receiving self-directed support per 100,000 population'[[140]](#footnote-140).

Evaluative data from the implementation of direct payments and individualised budgets highlighted system level issues that arose regarding the inconsistent implementation of these initiatives nationwide; inconsistencies which were reflected in take up rates[[141]](#footnote-141). The influence of frontline staff was considerable, with evidence suggesting that some staff had not received sufficient training regarding these initiatives. Where staff had received training, some remained cautious of self-directing options and raised concerns regarding issues of risk, capacity and vulnerability[[142]](#footnote-142). Strong leadership within local councils, staff training and the provision of accessible information were all identified as facilitators of implementation[[143]](#footnote-143).

Evaluative data on the cost of personal budgets in the UK has been described as 'patchy' and confounded by the fact that the mere introduction of a new scheme is likely to identify unmet need, increase demand and consequently result in an increase in costs[[144]](#footnote-144). In addition, evaluations of the financial cost of such schemes traditionally fail to incorporate additional costs such as start-up costs and the hidden cost of informal supports[[145]](#footnote-145). While there is a lack of evidence on the actual cost implications of introducing personal budgets, studies have reported reductions in cost between traditional services and self-directed options of approximately 10%[[146]](#footnote-146),[[147]](#footnote-147). These potential savings are likely to capture the trade-off between the price set by local councils for personal budgets and the additional cost of providing them[[148]](#footnote-148).

## 2.5 The impact of transitioning to self-directed services

The transition from direct service delivery to one of self-directed service delivery is a considerable paradigm shift. Mindful that there is no 'one model' within the English context, but rather 150 similar but different approaches to individualised supports offered across the local councils, the introduction of any model will have major implications for the manner in which commissioners and service providers conduct their business[[149]](#footnote-149). Advice from the UK Department of Health is that block contracts to providers should cease and that direct commissioning arrangements should become more strategic, permitting local councils to engage in 'spot' purchasing for individual support packages. Commissioning should be multi-level, examining regional needs over a three to ten year outlook, local needs over a one to two year outlook and individual needs via self-directed commissioning[[150]](#footnote-150).

While the data are limited, trends in the UK suggest that as individuals move away from traditional to self-directed services, there is a move from residential services to mainstream tenancies; there is greater demand for personal assistants and informal support; there is an increase in the purchase of supports relating to leisure pursuits (e.g. gym membership) and personal growth (e.g. evening classes); and there are a small number of people who use their budget to purchase innovative supports (e.g. football season ticket)[[151]](#footnote-151). Notwithstanding these developments, there remains a demand, albeit limited, for traditional service provision. As these transformations occur, research by Deloitte & Touche[[152]](#footnote-152) has indicated that it is likely that the development of an infrastructure to support this new model will lag behind; specifically they identify a 'temporary gap' in the supply of services such as advocacy and information services.

Service providers will need to take cognisance of this new landscape and be driven in their development by those who avail of their services[[153]](#footnote-153). There will be an increase in 'back room' costs as administrators who formally managed one large block contract are now responsible for the management of individualised contracts for each person in receipt of a personal budget. Accounting and IT systems will be required that are capable of monitoring the use of personal budgets in alignment with individuals' support plans and delivering and monitoring payments as required. Information will need to be collated for potential service users regarding the types of services provided, including new packages of support, and the respective costs of those packages. This will require services to break down the cost of various elements of service provision and outline exactly what it being provided, at what cost. Costs will need to be accurate, competitive, clear, inclusive of contingencies and take cognisance of hidden costs such as volunteer time. This information will need to be presented in a manner that is accessible and easy to use.

A likely development in the emergence of personal budgeting systems is the development of brokerage services. A UK Department of Health publication on good practice in brokerage[[154]](#footnote-154) defines the varied roles of a broker as providing supports in completing assessments and receiving an indicative budget, devising a plan, identifying funding sources, arranging housing, accessing community supports, coordinating support, vetting personal assistants, negotiating with providers, and completing monitoring and administration tasks. Brokerage organisations can be block funded by local councils, or can be paid for from an individual's personal budget. Critics have questioned the role of service providers as brokers on the grounds that a conflict of interest may exist whereby a broker who has supported an individual to obtain a personal budget may then become the beneficiary of that budget. Some local councils (e.g. West Sussex) have developed protocols to ensure the independence of brokerage services, while others are developing accreditation and training services in this area (e.g. Lancashire and Cheshire).

The introduction of personal budgets is also likely to impact on the workforce of social care support workers who may previously have been classified as statutory or voluntary sector employees, but who now will expand to include personal assistants, carers, volunteers, advocates and brokers[[155]](#footnote-155). 'Hybrid roles' are expected to emerge where professionals broaden their remit beyond their traditional roles. Social workers, for example, may spend less time involved in assessment and more time engaging in non-traditional support areas such as housing or employment. For those who will be employed directly by individuals in a personal assistant capacity, issues such as employment rights, salary scales, health and safety etc., will need to be comprehensively addressed. Concerns have been expressed in the UK that personal assistants and homecare agency staff can work in conditions where opportunities for training are rare and pay conditions are poor. The current profile of those working as homecare agency staff, for example, is a largely female migrant workforce with high turnover[[156]](#footnote-156). It is an unfortunate but possible consequence of increasing the personalisation of supports, that staff who were formally employed in the statutory and voluntary sector may migrate to the private sector where jobs are more plentiful but conditions less favourable.

Regulatory bodies and systems will also need to take cognisance of the changes in support services[[157]](#footnote-157). The Care Quality Commission (CQC) in the UK is currently developing a new regulatory framework for health and adult social care across public, private and voluntary sectors[[158]](#footnote-158). All health and adult social care services will be required to register with the CQC and will be monitored for compliance against newly developed essential standards of quality and safety. Currently, registration does not cover situations where an individual is supported by a family member or friend. Details of the new framework are expected by May 2011[[159]](#footnote-159). While the regulation of personal assistants is currently being explored by the General Social Care Council, the Department of Health are clear that 'ultimately the local authority has a statutory duty of care'[[160]](#footnote-160).

Finally, with regard to governance, local councils need to put structures in place to address issues such as risk management, the potential misuse of funds and the introduction of appropriate auditing practices. In addition, councils are being requested to monitor outcomes, both organisational and individual[[161]](#footnote-161). Organisational outcomes include cost, risk, choice and control and the extent to which self-directed services align with other council objectives. Individual outcomes are most likely to be identified via individual support plans benchmarked against a baseline assessment.

## 2.6 The Right to Control

The most recent personalisation initiative specifically targeted at individuals with disabilities is entitled "Right to Control". The initiative stems from Part 2 of the Welfare Reform Act 2009[[162]](#footnote-162) which 'confers regulation-making powers that can be used to give adult disabled people greater choice and control over the way in which relevant services are provided'. The Act makes provision for the implementation of pilot projects, to be completed over a three year period, which will ascertain the impact of new initiatives on the lives of people with disabilities and the financial impact on relevant authorities.

Five million sterling has been made available to organisations in seven local councils participating the pilot[[163]](#footnote-163),[[164]](#footnote-164). Following a period of selection, five councils began their pilot in December 2010, a further two will commence in the spring of 2011. Within each local council area, termed Trailblazers, individuals who are identified as being eligible for any one of six funding streams will be entitled to an array of support options from their local council. Trailblazers must aim towards a system where, irrespective of the number of grants an individual is eligible for, s/he will only have to undergo one assessment and one review process. The legislation requires Trailblazers to inform eligible individuals about their 'right to control' and direct them to local organisations that provide independent advocacy and brokerage services. Individuals have a right to know the level of support they are eligible to receive, have control over their choice of support, and decide on the outcomes they wish to achieve with their support. Trailblazers have a duty to develop support plans that clearly specify the individual's budget, the outcomes to be achieved, the supports that will be purchased, the manner in which the budget will be managed or contributed to, and the process of review.

Right to Control provides an opportunity for further refinement to the transformation of self-directed services for people with disabilities in the UK. It will explore new territory such as the option of using outcome-based performance indicators based on an individual's top three most important personal goals (e.g. learning to garden, visiting France, using the library) as an alternative to traditional policy-related indicators such as the number of persons receiving support or the waiting time for assessments[[165]](#footnote-165). It will harness the opinion of a wide array of stakeholders via a web community[[166]](#footnote-166) where experiences can be shared and supported across pilot sites. In addition, it will undertake an extensive evaluation based on a feasibility study which calls for either a matched area control design or randomised control trial design[[167]](#footnote-167).

Initiatives such as Right to Control continue the UK's commitment to the personalisation of social care supports set out in the 2007 cross-sectoral concordat 'Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care'. The transformation from professionally-led organisations to self-direction aims to empower individuals to have maximum choice and control in their lives. These advances are now extending beyond adult social care to NHS health services, where the Department of Health will shortly pilot a system of direct payments in healthcare[[168]](#footnote-168). For those with disabilities, the Green Paper entitled Shaping the Future of Care Together[[169]](#footnote-169) reiterates the future direction of support services for people with disabilities. This Government paper calls for a new system of support which is fair, simple, affordable, underpinned by national rights and personalised to individual need. Without doubt, this is a period of unprecedented change throughout the UK health and social care sector. Mindful of the cultural context within the UK shaping these changes, there are valuable lessons to be gleaned from these experiences for other jurisdictions embarking on a journey of personalisation.

## 2.7 UK: Key summary points

* The UK adult social care system is currently undergoing radical transformation towards a system of personalisation whereby individuals will have the right to have their needs assessed in a standardised manner, to be informed of the proportion of their support costs that will be paid for, and to use those costs in a portable manner irrespective of location.
* A Common Assessment Framework is being considered to coordinate and reduce duplication of assessments conducted in social care and related services.
* Assessments are moving from a traditional, professionally-led system towards a more individualised approach which is person-centred, completed in conjunction with carers, uses self-assessment tools, and is conducted within flexible timeframes.
* Local councils are obliged to offer eligible individuals the option to self-direct their own services and are currently in the process of implementing resource allocation systems based on personal budgets for non-residential social care. A target of 30% of eligible individuals transferring to personal budgets is set for March 2011.
* The determination of personal budgets uses a prospective model whereby an indicative budget is calculated prior to the development of a support plan.
* Individuals may choose from a number of options regarding the manner in which their budget will be managed, including requesting the local council to arrange their support package, establishing an Individual Service Fund where the budget is held in account, to self-commissioning of services via options such as direct payments.
* Resource Allocation Systems (RAS) vary across local councils but typically apply either the ADASS or In Control model; in fact, the ADASS model emanates from In Control.
* Evaluative data of the cost of personal budgets is described as 'patchy' but some small scale studies report reductions in the cost of support packages of approximately 10%. The studies note that the mere introduction of a new scheme is likely to identify unmet need and consequently, increase demand.
* The impact of transitioning to self-directed services for specialist disability providers has been pervasive.
* Clear descriptors of support options, with respective costs, are now required by budget holders as they develop support plans.
* New services have emerged including advocacy, brokerage and information services.
* Issues of governance, regulation, and the impact of self-direction on employees are currently under consideration.
* Investment in pilot initiatives such as Right to Control continue to refine the new system of personalised supports.

# 3. Implementing the nationwide introduction of individual budgets: Experiences in the USA

## 3.1 Publicly Funded Disability Support Services

Disability services throughout the United States are largely funded via Medicaid[[170]](#footnote-170), a grant-in-aid funding stream managed at federal level by the Centers for Medicare and Medicaid Services (CMS), a division of the U.S. Department of Health and Human Services. While CMS provide guidance on the federal requirements for Medicaid funding, each state takes responsibility for local implementation. Medicaid is the largest purchaser of long-term services and supports for people with disabilities[[171]](#footnote-171) and older persons in the US, accounting for almost half of all expenditure on long-term services. By 2006, Medicaid expenditure for long-term care services approached 100 billion[[172]](#footnote-172).

Historically, Medicaid provided states with funding for institutional-based care for people with disabilities under the 'Intermediate Care Facility for People with Mental Retardation' (ICF/MR) program[[173]](#footnote-173). ICF/MR programs provided federally matched funding to state institutions; a funding stream which grew substantially from its inception in 1971 to the early 1990s, from which time it has been steadily in decline. Much of the Medicaid funding has now transferred to its 'Home and Community Based Services' (HCBS)[[174]](#footnote-174). HCBS 'waivers', introduced by Medicaid in 1981 under Section 1915(c) of the Social Security Act, enable states to fund home and community based services as an alternative to institutional provision, and thereby 'waive' some of the requirements specific to the funding criteria applied to ICF/MR services. Currently, approximately three-quarters of all Medicaid HCBS waiver expenditure is used to purchase supports for people with developmental disabilities who require 24 hour supports, with the remaining expenditure supporting those with physical disabilities and older adults[[175]](#footnote-175). An estimated 560,000 persons with developmental disabilities are supported through Medicaid waivers nationwide[[176]](#footnote-176),[[177]](#footnote-177). Individuals seeking HCBS funding from Medicaid must be assessed as requiring a level of support that would deem the person eligible to receive ICF/MR supports[[178]](#footnote-178), but who choose instead to use this funding to finance community-based supports. By the year 2000, HCBS spending matched that allocated to ICF/MRs, and it continues to surpass it in the intervening years[[179]](#footnote-179). By 2007, Medicaid HCBS spending, at $42.3 billion, comprised 41.7% of all Medicaid long-term services expenditure[[180]](#footnote-180).

Medicaid waivers are a major driver of disability service provision throughout the US and are perceived as a largely positive influence in encouraging flexible and innovative disability service provision[[181]](#footnote-181). Waiver programs are typically available in two formats: Support Waivers, which offer average annual allocations in the region of $14,000, and Comprehensive Waivers, which offer more substantial annual allocations in the region of $47,000[[182]](#footnote-182). States are empowered with a degree of latitude in the development of their own waiver programs. While there is a CMS requirement that the per person cost of the waiver is no greater than the per person cost of ICF/MR type provision, it is the states themselves who decide on the eligibility and scope of their waivers. States have discretion in setting eligibility criteria and can, for example, limit the coverage of the waiver program by restricting funding to specific populations or regions within their state. Typically, eligibility for persons with disabilities for waiver programs is determined during an admissions process which establishes whether those presenting have a diagnosis of 'mental retardation' or related disability condition and whether they require the level of support provided by an ICF/MR. Most states use either a categorical-based criteria whereby specific conditions are referenced (e.g. autism spectrum disorder, cerebral palsy, intellectual disability) or use a functional-based criteria (e.g. based on an individual's adaptive ability) to determine eligibility[[183]](#footnote-183). Typically, those seeking disability support services tend to have significant functional limitations that require supports beyond those provided by family. Publicly funded developmental disability services, for example, are estimated to serve only 20-25% of the estimated five million persons with developmental disabilities resident in the United States[[184]](#footnote-184).

Demand for publicly funded disability support services is increasing throughout the US, notably at a rate greater than population growth alone. Factors contributing to this increased demand include an increase in life expectancy of both persons with disabilities and their caregivers, and an increase in class-action litigation, most notably with regard to the expansion of services to those on waiting lists, and the non-compliance of public services to meet federal requirements[[185]](#footnote-185). In addition, a major factor compounding the demand for disability support services is the pressure on states to reduce their expenditure on services. The Center on Budget and Policy Priorities, for example, reported in 2008 that 43 states forecast state budget gaps totalling over $78 billion[[186]](#footnote-186). Many states have already cut public health programs, educational programs and rehabilitative, medical and homecare services specific to persons with disabilities. In light of budget shortfalls throughout many states in the US, additional funding to expand Medicaid services to meet demand is thus most unlikely; rather states are charged with seeking alternative, and more efficient uses for the federal matched funding they receive. In the face of these challenges, states are seeking methods to provide greater choice and control to those seeking services while ensuring that resources are allocated more efficiently and equitably to meet individual support needs[[187]](#footnote-187).

## 3.2 The Development of Consumer-Directed Services

As in other jurisdictions, the traditional funding model for disability services throughout the US is 'fixed dollar contracts', that is, block funding between state agencies and disability providers. The model is criticised on the grounds that it ties funding to service providers, discourages the entry of new providers into the market, and undoubtedly makes it difficult for persons with disabilities to change provider[[188]](#footnote-188). In patterns reflected world-wide, this traditional model is gradually being replaced by individualised services that aim to provide increased levels of choice and control to people with disabilities. Throughout the United States the term 'consumer-directed' services is most commonly used to refer to self-directed service options[[189]](#footnote-189). Essential elements of consumer-directed services are identified as person-centred planning, individual budgets, self-directed support and quality assurance and improvement[[190]](#footnote-190).

Based on the premises of normalisation[[191]](#footnote-191), self-determination[[192]](#footnote-192) and person-centred supports[[193]](#footnote-193), the move towards consumer-directed services in the US was initiated in large part by the advocacy of individuals and their families[[194]](#footnote-194). As early as the 1970s, parents of individuals with severe and profound levels of intellectual disability resident in Woodlands, British Columbia, developed one of the pioneering initiatives in individualised funding. In calling for the deinstitutionalisation of their family members, the parents successfully argued that funding for community living, based on individual need, should be allocated directly to family[[195]](#footnote-195). At the same time, a group of individuals with physical disabilities in Berkeley, California used funds previously provided by the state for residential supports, to instead employ their own personal assistants within the local community[[196]](#footnote-196). These pioneering models of individualised funding, which are deemed to have heralded the worldwide shift towards self-directed services[[197]](#footnote-197), aimed to change the fundamentals of funding from one where state funding is used to purchase services from provider organisations who then deliver to individuals requiring supports, to one where state funding is delivered directly to individuals who then either purchase services from provider organisations, or use the funds to hire their own personal assistants[[198]](#footnote-198).

Consumer-direction options within Medicaid HCBS programs commenced in the 1970s with the introduction of personal assistants in a small number of states[[199]](#footnote-199). Throughout the 1980s and 1990s the number of states that offered self-direction through Medicaid funded programs steadily grew. Of particular note in the development of these programs was a series of 'Self-Determination' demonstration projects funded by the Robert Wood Johnson Foundation in the early 1990s. These demonstrations commenced with an experimental project in New Hampshire in 1993, and aimed to give individuals greater control over the services they received through the use of person-centred planning and individual budgets. Independent counselling services, termed Support Broker Services, were established to assist participants in their selection and management of support packages, and 'fiscal intermediaries' were introduced to serve as agents to assist in the employment of support staff. These demonstrations provided an early evidence base that the movement towards individualised funding resulted in greater levels of choice and control for people with disabilities at no additional cost[[200]](#footnote-200).

The Robert Wood Johnson Foundation continued its support of consumer-directed services through its sponsorship of the 'Cash and Counseling' demonstration programs in conjunction with the US Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation (ASPE). Individuals participating in Cash and Counseling were eligible to receive a monthly cash amount to purchase goods or services they deemed essential. While the cash amount could be received either directly or by an intermediary, virtually all recipients chose the latter and paid a small fee for a fiscal agent to manage their fund. Peer professionals were available to assist recipients in their decisions[[201]](#footnote-201). The fact that so many participants did not receive a cash payment per se, has led some commentators to suggest that the program was more a demonstration of vouched expenditure with capped payments than of consumer direction[[202]](#footnote-202). While Cash and Counseling was the title of the grant awarding scheme, each participating state has tended to rename their own specific program over time, such as the 'Independent Choices' program in Arkansas and the 'Personal Preference' program in New Jersey[[203]](#footnote-203). A comprehensive evaluation of the Cash and Counseling scheme highlighted positive benefits for both participants and the staff they employed[[204]](#footnote-204).

Following from these demonstrations programs, CMS launched its own consumer-direction program, 'Independence Plus', in 2002. This stand-alone waiver encouraged states to offer individuals with long-term support needs self-directed options including individual budgets, the option to employ support staff directly and brokerage services. An important caveat to access Independence Plus funding is that states must demonstrate to CMS that their determination of individual budgets is based on sound quantitative methods and is applied consistently across jurisdictions[[205]](#footnote-205). By 2005, CMS revised the standard 1915(c) waiver application process to fully integrate self-directed service options. That is, states can now offer self-directed options within any HCBS waiver programme. As of 2009, over 90 Medicaid waivers, available in 32 states[[206]](#footnote-206), offer some form of consumer-directed services[[207]](#footnote-207). Without doubt, self-direction is now an integral component of HCBS waiver programmes.

Mindful that states differ markedly in the types of consumer-directed programs they offer, some basic elements are common across differing Medicaid HCBS programs. States that offer consumer-directed services, for example, must ensure that those presenting for support services are offered not only self-directed services, but also the option to receive services in a traditional format, whereby the service is delivered and managed solely by a provider organisation. This requirement acknowledges the fact that not all individuals will have a preference to self-direct their own services. States are also obliged to ensure that, for those wishing to transfer from traditional to self-directed services, there is no disruption in the continuity of services provided during the transition. Those who opt to direct their own services should be offered the opportunity to select those who will be involved in planning their supports, and should have free choice over who will deliver those supports. It is a federal requirement that participants in self-direction programs undergo an individualised needs assessment carried out by a professional assessor who may be a case manager working for the state or a service provider (self- or agency-employed). In most states, individuals who self-direct are awarded an individual budget, comprising part or all of their Medicaid HCBS funding, and can use this fund to purchase selected goods and services of their own choosing. Typically, the fund is managed with the aid of external counsellors and financial management services. Individuals must be offered the option to directly employ their own support staff. Finally, states must provide certain basic safeguards for those directing their own services. These include ensuring a continuity of support for those transitioning from traditional services, providing supports to ensure funds are not prematurely spent, and ensuring that there is a back-up plan in the event of a breakdown in service delivery[[208]](#footnote-208).

A useful dichotomy in describing the differing consumer-directed programs offered by Medicaid, is the classification of programs as either 'employer authority' or 'budget authority' models[[209]](#footnote-209). Employer-authority style programs must offer participants, or a nominated representative, the opportunity to hire, manage and dismiss their own employees; that is, they must be given the authority to become an employer and to participate in all elements of employment such as recruitment, selection, training, and the negotiation of schedules. In addition, individuals must be offered a role in the payment of their staff, whether at the level of approving timesheets or of co-signing payment cheques. The rate of pay is fixed in some states and as such is non-negotiable. Others provide flexibility to individuals or families to determine pay rates providing they conform to specifications such as 'within normal and customary costs'. The person's individual allocation is typically an authorised amount of support, defined in a set number of hours, to be paid at an agreed rate. States typically provide guidance on the direct support staff an individual may employ. In general, direct support staff must be over 18 years of age, not a spouse or legal guardian of the individual and must not have a criminal record[[210]](#footnote-210). There are, however, always exceptions as in the case of Florida and Minnesota, for example, where the choice of direct care staff includes family members. Typically, employees working in consumer-directed programs are poorly paid and receive few fringe benefits. They do, however, report high levels of job satisfaction when compared with support staff working within traditional services[[211]](#footnote-211).

In contrast to these programmes the 'budget authority' model allows participants to negotiate a wage rate with their prospective employee. In the US, this flexibility is perceived as providing the participant will a greater level of choice of employees, as the person may offer a higher wage rate to attract a more suitable employee. The wage rate must conform to statutory requirements such as minimum wage rates or employee insurance. The budget authority model provides additional flexibility by permitting participants to use their funding not only for employment services, but also for other goods or services that meet their needs. These goods and services typically comprise assistive technology, home care services such as laundry or meal services, medications, transportation options and home modifications. The types of goods and services that may be purchased using an individual budget are specified within each programme[[212]](#footnote-212).

## 3.3 Calculating Individual Budgets

The term "individual budget" has long been used within developmental disability services to apply to a general allocation of funding assigned to an individual, irrespective of whether the individual has the opportunity to self-direct. While definitions vary, individual budgets are defined by Medicaid as 'an amount of funds that is under the control and direction of a participant when the state has selected the state plan option for (the) provision of self-directed personal assistance services. It is developed using a person-centered process and is individually tailored in accordance with the participant's needs and personal preferences as established in the service plan'[[213]](#footnote-213).

CMS does not prescribe a methodology for the manner in which states calculate individual budgets, and consequently there is wide variation in their design throughout the US. Regardless of the specific method a state selects, the core components of the individual budgeting process are to determine individual need, devise a plan to meet that need, determine a budget amount, and finally, agree an authorised spending plan[[214]](#footnote-214). In applying for Medicaid funding from CMS, states are required to outline how individuals and their families will be informed by the state of the methodology used to determine their individual budget, the total value of the budget, any policies applicable to the person's management of their budget and the mechanism by which any adjustment to the budget amount will be addressed[[215]](#footnote-215). In particular, CMS requires states to evidence that the methodology used to determine individual budgets is 'data based' and applied in a consistent manner across the state or jurisdiction. While 'data based' is not defined per se[[216]](#footnote-216), CMS stipulate that individual budgets must be determined from actual cost and utilisation data derived from reliable sources.

Of the differing methodologies used to determine individual budgets throughout the US, some meet the CMS criteria better than others[[217]](#footnote-217). In some states historical data, such as the Medicaid cost and utilisation data derived from the Medicaid Management Information System (MMIS) database, is used to determine individualised allocations. Essentially, the data comprise billing information which is historical in nature and is used as a predictor of future cost. The advantage of this method is that the derived costs are likely to be budget neutral given that they are based on previously incurred costs. The disadvantages, however, are numerous. The suitability of historical data to predict future usage is questionable as it is unlikely to capture changes in individual need over time; the data may be difficult to access and interpret given that their primary function is not the determination of individual budgets; and, the level of unmet need and predictions for those who are new to the system cannot be determined from a system of this nature. In short, the use of historical data from the MMIS may reach the CMS criteria of being a source of actual cost and utilisation data, however, its reliability for the purposes of determining individual budgets must be questioned.

More sophisticated techniques are currently being introduced throughout the US which use mathematical formulae to determine individual budget allocations[[218]](#footnote-218). The methods require the availability of a considerable amount of data and the gathering of new data and, as such, are labour intensive to develop. The relationship between these data and the cost of service provision is then determined. The data are likely to include variables at regional level (e.g. per capita income), funding sources (e.g. state funding), use of support services (e.g. supported employment), residential arrangements (e.g. semi-independent living with staff) and level of individual support need, typically measured using a standardised assessment tool (e.g. in a study combining data from Wyoming, Nebraska, South Dakota and Montana, the ICAP[[219]](#footnote-219) was selected as a standardised assessment measure of individual support need). These variables are collectively used as predictors of cost; that is, a statistical equation (multiple regression) determines the power of these variables to predict the reimbursement cost to the state for the provision of disability support services. The equation calculates the proportion of costs, expressed as a percentage, which can be explained by the contributing variables. Predictor models explaining 70% or higher of reimbursement costs would be considered respectable. These models are then used to produce individual funding amounts based on the person's scoring on each of these variables.

The table below, (adapted with kind permission from Campbell et al., 2005[[220]](#footnote-220)), provides a calculation for one individual which culminates in a monthly reimbursement rate of $2,635.65. The table illustrates how each of the predictor variables impacts on the calculation of the individual budget for a hypothetical person, aged 57, who lives in a group home residence, attends an adult day centre, and participates in part-time supported employment. Starting with a standard base amount of $1,694.12 per month, each variable either adds or subtracts an allocation from the predicted monthly reimbursement rate. The individual's 'Broad Independence Score' on the ICAP, for example, shows a negative figure of $1,405.95 indicating that the individual has a high level of independence which results in a deduction of this amount from the monthly reimbursement rate. In contrast, an amount of $1,075.33 is added to the budget per month based on costs associated with the person's residence, in this case a group home. In this way, an individual amount is determined for participants based on their responses to each of the predictor variables.

These calculations are 'budget neutral' for the overall budget being allocated. That is, they ensure that the overall predicted budgetary amount generated by the formula will be exactly the same as the overall current expenditure[[221]](#footnote-221). While this method may ensure that resources are distributed fairly among those receiving supports, the model does not ensure that the allocation per individual is adequate to meet need. In addition, differences will be apparent for almost all individuals between their predicted costs and the actual costs of their support package. These disparities balance out in the overall budget as the underestimated expenditure will match exactly the overestimate expenditure.

|  |  |  |  |
| --- | --- | --- | --- |
| Table 1: Spreadsheet to calculate monthly reimbursement rates**.** | | | |
| Column A | Column B | Column C | Column D |
| Variable | Parameter estimate | Variable Value | B X C |
| Base amount | 1,694.12328 | Yes | 1,694.12 |
| **Geographic Measure** |  |  |  |
| Per-capita income | 0.01051 | $22,000 | 231.20 |
| **ICAP Summary Scores** |  |  |  |
| Broad Independence Index | -3.09680 | 454 | -1,405.95 |
| General Maladaptive Index | -6,28330 | -22 | 138.23 |
| **ICAP Other Measures** |  |  |  |
| Age | -3.76168 | 57 | -214.42 |
| Speaks? | -168.92795 | Yes | -168.93 |
| Need for doctor/nurse? | 43.78951 | Yes | 43.79 |
| Diagnosis = autism? | 295.11821 | No | 0.00 |
| Diagnosis = mental illness? | 141.54549 | No | 0.00 |
| **ICAP -Environments (Residential)** |  |  |  |
| Living with family? | -298.39317 | No | 0.00 |
| Group Residence? | 1,075.33145 | Yes | 1,075.33 |
| State institution? | 5,587.20481 | 0 | 0.00 |
| **ICAP -Environments (Daytime)** |  |  |  |
| Day activity center? | 64.94696 | Yes | 64.95 |
| Supported Employment? | -133.60095 | Yes | -133.60 |
| **Services Supported/Provided** |  |  |  |
| Adult Residential? | 658.21978 | Yes | 658.22 |
| Adult Daytime? | 652.70797 | Yes | 652.71 |
| **Funding** |  |  |  |
| State Funding? | -325.22713 | No | 0.00 |
| **Predicted Monthly Reimbursement Rate** |  |  | **$2,635.65** |

Table is presented with kind permission of Edward M. Campbell; from Campbell, E., Fortune, J., Frisch, J., Heal, L., Heinlein, K., Lynch, R., & Severance, D., (2005). Predictors of Expenditures in Western States. In Stancliffe, R.J., & Lakin, K.C., (2005) Costs and Outcomes of Community Services for People with Intellectual Disabilities. Paul H. Brookes Publishing Co., Baltimore MD (pp.190).

## 3.4 The DOORS Project, Wyoming

Perhaps one of the best known examples of this type of individual level model is the DOORS project in Wyoming[[222]](#footnote-222). As with other states throughout the US, Wyoming undertook a policy of deinstitutionalisation throughout the 1990s and began an extensive development of community-based services funded through Medicaid waivers. The availability of Medicaid federal funding did, however, require a change from Wyoming's traditional funding mechanisms, whereby services were funded through a combination of rate schedules, capping of overall costs and ad hoc negotiations with provider organisations, towards a system whereby funding was related to individual support need. An initial attempt to link funding to need was based on a model previously implemented in Utah, whereby the ICAP, as presented in the example above as a standardised measure of support need, was used to classify individuals to one of five levels, each of which was defined by staffing ratios and was subsequently costed to a daily rate. The model was deemed not to reflect individual need and a new DOORS model was developed to generate individual budgets within the confines of the overall available funding.

The DOORS model aimed to introduce some major alterations to the structure of disability funding in Wyoming. Funding would be calculated for each individual, as opposed to persons being allocated to a level of funding; individuals would have the authority to select the service of their choice; there would be an uninhibited free selection of service providers; and the model would employ open, as opposed to slot-based contracting to encourage the free entry of providers. In a similar manner to the calculation example presented above, the DOORS model uses ICAP scores, service utilisation and an array of other relevant variables to predict individual budgets. At its inception in 2003, the model comprised 22 variables of which ICAP scores and service utilisation predicted up to 75% of reimbursement costs. To ensure the validity of the model, support needs assessments are undertaken at least every three years, and the findings are incorporated back into the equation which is then released in an updated model. Changes to the model are generally minimal and as such the model is deemed to be accurate for most individuals. As with other models, special consideration is required for those who are identified as having extreme support needs in comparison with their peers. An appeal process is available in such cases via the State Level of Care Committee (SLOCC) where additional funding may be requested.

The DOORS Project provides an example of the development of Individual-based Budget Allocations, also known as IBAs. These models can be contrasted with those which aim to develop Level-based Budget Allocations, or LBAs. Essentially, both resource allocation models systematically analyse the relationship between individual support need and cost (or a proxy of cost such as direct support hours), however, while IBAs produce a unique allocation for each individual, LBAs assign individuals to a particular level of allocation. The number of levels and their composition are dictated by the dataset and are typically tested against two main service categories, residential services and day services. The defined levels are thus composed of individuals who are assigned to each level, and who by definition, are apportioned the same allocation as all others within that level (unless finer distinctions are made within each level) [[223]](#footnote-223).

## 3.5 The ReBar Project, Oregon

The ReBar project in Oregon provides a useful example of the transition from traditional to level-based funding options[[224]](#footnote-224). Oregon has a similar demographic profile to Ireland, with a population of 3.5 million persons resident in 36 counties. State funding is provided for locally-managed community-based services. County governments typically provide case management services directly and contract with provider organisations or individuals for the delivery of other services. A comprehensive waiver supports approximately 5,500 persons with developmental disabilities who require 24 hour support. Prior to the ReBar project, Oregon had no individualised data on historical or current support needs, nor did it have data on the cost of the disability services it provided. Oregon is now in the process of radically reshaping the services to three core groups on the waiver: those resident in group homes, those resident in supported living, and those receiving employment and community inclusion supports. Oregon aims to transform these services from a 25 year old 'slot-based' system to a new system that will develop individual budgets for 3,500 persons, standardise rates for services, and develop a quality management system. ReBar has received funding for five years from CMS through its System Transformation Grant to support these developments. The Human Services Research Institute[[225]](#footnote-225) (HSRI) provide technical assistance to the project.

To date, pilot data has been gathered on a representative sample of 400 persons supported by 75 provider organisations, located in 11 different counties. The Supports Intensity Scale (SIS), developed by the American Association on Intellectual and Developmental Disabilities, has been selected as a standardised assessment tool to gather individual support need data[[226]](#footnote-226). Supplementary demographic data that was deemed to impact on cost was also gathered on participants. These data included information on medical needs, whether the person is deemed to be at risk of crime in the community, and whether the person engages in behaviours that challenge[[227]](#footnote-227). In addition to these demographic data, information for the pilot was also gathered on behalf of each individual using the Individual Service Survey (ISS)[[228]](#footnote-228), an online questionnaire that provider organisations complete detailing the support services used by each participant, whether group home supports, independent living supports or employment and community inclusion support services. The group home residential section of the questionnaire, for example, seeks detailed information on the number of co-residents in a dwelling, the number of direct care staff, the staffing hours, the day services provided, etc. For the supported living services section, information is requested on the number of direct care staff support hours apportioned to each participant. The third area of data gathering in the ReBar pilot, in addition to the SIS and ISS, is the Provider Cost Survey (PCS)[[229]](#footnote-229). This survey, developed by Burns & Associates, gathers financial data from providers for a specific fiscal year. Organisations are required to provide considerable financial data, sufficient for the purpose that services can be validly costed to determine reimbursement rates, rate models and rate setting methodologies. The collection of data is due for completion in mid 2011, having commenced in 2008. Assessment units were established in ten offices statewide specifically for the purposes of completing the SIS assessments. Each assessor was charged with completing a total of eight assessments per month. Simultaneous to the data gathering phase, policies and procedures are being developed regarding interview guidelines, person centred planning, rate setting guidelines, governance of individual budgets etc.

Within 30 days of completing an assessment, individuals participating in ReBar are informed of a level of funding, termed a 'tier', which is determined to best represent their needs in their particular residential setting[[230]](#footnote-230). There are six tiers, each of which contains several rates that reflect appropriate funding for a person of a given level of support need, adjusted by the person's residential circumstances. As with most models, exceptional support needs are addressed outside the established rates. The table below presents the six tiers used for persons who are resident in group home settings. Each tier represents a level of support need, from lower to higher (1-6). Each tier is further classified by the number of persons who co-reside in the person's dwelling. This example, devised in 2008, presents monthly individual budget amounts ranging from $2,777 to $15,011. The budget amount represents the maximum monthly amount the person's residential provider can bill for supports and services provided throughout the month.

The ReBar Project continues its progress and is expected, by June 2011, to have completed assessments and finalised determinations on budgets for all 2,500 residents in group home settings.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Table 2: Funding tiers employed by ReBar for people on Comprehensive Waiver who are resident in Group Home Settings. | | | | | | | |
| IBA Tier | Tier 1 | Tier 2 | Tier 3 | Tier 4 | Tier 5 | Tier 6 | Exceptional Support Review |
| 9 or more people | 2,777 | 2,780 | 2,781 | 3,236 | 3,999 | 4,529 |
| 6-8 people | 3,641 | 3,973 | 4,294 | 5,195 | 6,420 | 7,271 |
| 4-5 people | 4,995 | 5,758 | 6,222 | 7,528 | 9,377 | 10,996 |
| 3 or fewer people | 4,995 | 5,758 | 6,222 | 11,238 | 12,805 | 15,011 |

Table taken from Oregon Department of Human Services (2008). ReBar Program Tools: Assessment and Individual Budget Amount (IBA) Implementation. Available at http://www.oregon.gov/DHS/dd/rebar/docs/cntyprov\_prep.pdf, Accessed 16th February 2011.

## 3.6 Rate Setting for Licensed State Providers

An important consideration in the development of consumer-directed services, and the determination of individual budgets, is the issue of rate setting. In traditional block funded services, the contract between state and provider typically stipulates a negotiated cost agreed between the two parties for the delivery of services, usually in units such as 'workshop', 'group home', or 'activity centre' [[231]](#footnote-231). Within the new model, contracts between individuals and providers will require robust estimates of the individual cost of support services. Rate-determination processes will need to ensure that individual budgets based on support need are appropriately aligned to reimbursement rates.

CMS require that standard reimbursement rates for state licensed or certified services apply across all areas of a state and that any differences in cost have a transparent rationale that is clearly communicated to potential consumers (e.g. expense incurred in delivering services in remote areas)[[232]](#footnote-232). In order for a state licensed or certified disability provider to be reimbursed, or 'billed', they must present an itemised bill listing the services that have been provided over a specified time period, typically on a monthly basis. The bill should specify the exact services received, with details of dates, locations, etc. The provider can only bill for services that are availed of; they cannot bill for a non-attendance. The unit of measurement for billing is dependent on the specific service being provided, that is, community inclusion activities may be billed per hour, respite may be billed per half day, transport may be billed per mile, etc. In fact, in some models the unit of billing is based on outcome or performance. Irrespective of uniting, all billing must comply with Medicaid regulations which state that costs must be based on 'customary charges', be cost effective, be documented in the public domain, be exclusive (a provider cannot bill for support services that are already paid for), and there is a stipulation that 'Medicaid is the last dollar', that is, Medicaid will not pay for a service that is eligible from another source[[233]](#footnote-233). Bills are typically paid by a brokerage organisation who, on instruction from the budget holder, acts in a fiscal agent capacity. Individuals may choose their level of involvement in payment, whether signing and authorising payments or delegating these tasks to brokerage services[[234]](#footnote-234).

To determine reimbursement rates, states must distinguish between allowable (e.g. staffing) and non-allowable costs (e.g. pre-service staff training). Estimated rates, per one unit of service, must be determined based on actual expenditure for existing services, and on projected costs for new services. Projected costs must be updated with actual expenditure within a maximum of six months. The billing rate for one unit of service is typically effective for a one year period. The determined rates must then be made publicly available and are typically presented online. Rate tables for support services, brokerage and comprehensive in-home supports in Oregon, for example, are available on the Department of Human Services Website[[235]](#footnote-235). In tandem with developing these rate schedules, states are required to establish accounting and billing systems that can accommodate multiple and complex payments which comprise varying amounts and durations. They are also required to conduct regular reviews of rates charged to verify that they accurately reflect the cost of service provision.

## 3.7 Standardised Assessment Tools

The stipulation by CMS that states must implement a uniform rate-setting methodology, and their requirement that the determination of individual budgets is 'data based' and applied in a consistent manner, has led many states to seek a standardised assessment of support need tool that will ensure payment rates accurately reflect each person's support needs[[236]](#footnote-236). Some states have elected to design their own assessment tool. These tools typically have face validity, that is, they appear on face value to measure support needs, however, there is typically little psychometric evidence of these claims. In contrast, other states have adopted to select a standardised assessment tool of support need which may then be adapted for the purpose of resource allocation. Standardised measures of assessment include the ICAP and SIS as used in the DOORS and ReBar projects. These standardised measures are psychometrically robust and avoid any speculation that the findings may be subjective.

A highly comprehensive comparison of assessment tools was undertaken by the HSRI to guide the Colorado Division of Developmental Disabilities' choice of measure. Ten assessments[[237]](#footnote-237), including both state-developed and standardised measures, were compared on a number of key variables including scope, psychometrics, administration time, training, costs, and ongoing technical support. Three tools were examined in detail on the basis that they provided most potential; the ICAP, the SIS and the CAT (a Colorado state measure). A summary of these measures is presented in Appendix B. From these three measures, the SIS was deemed to be the most appropriate tool to support rate determination and funding allocations in Colorado.

The strengths of the SIS have applicability not only for Colorado, but for others seeking a valid and reliable measure of support need for resource allocation. The SIS comprises 86 items presented in three sections. Section One examines the frequency (how often support is needed, e.g. 'at least once a week'), time (how long it takes to provide support, e.g. less than 30 minutes) and type (e.g. ranging from monitoring to full physical assistance) of supports required. Section Two examines the person's level of protection and advocacy (e.g. self-management of money). Section Three examines the individual's exceptional medical and behavioural needs (e.g. seizure management). By 2010, SIS was in use in 12 states throughout the US as a disability service planning tool, with a further six states in the early phase of implementation. Internationally, the SIS is available in 14 countries, with translations into 12 native languages[[238]](#footnote-238). Field testing of a children's version for those aged 5-16 years is currently underway.

## 3.8 Looking ahead

Consumer-directed options are now firmly embedded within the array of support services available to persons with disabilities in the United States. While these services, to date, have been largely within the field of developmental disabilities, new options for state-funded self-directed services have arisen from the Deficit Reduction Act which expands HCBS service options beyond those who are deemed at risk of institutionalisation, as per the ICF/MR criteria. Individuals with mental health difficulties, previously excluded from HCBS funding may now be eligible. In addition, veterans are identified as a key population that are likely to benefit from the opportunity to self-direct, and indeed the Veterans Administration has recently expressed an interest in exploring this option for both those with short-term and long-term recovery needs[[239]](#footnote-239).

## 3.9 USA: Key summary points

* Community-based disability services throughout the US are largely funded by federal and state-matched funding under the Medicaid Home and Community Based Services (HCBS) Waiver Program.
* Increasing demand for disability services, at a time of budgetary shortfalls, is placing pressure on states to use their funding in more efficient and equitable ways.
* Consumer-directed services have a long tradition throughout the US, being pioneered initially by advocates and more recently being made available across all Medicaid HCBS programmes.
* Individual budgets are a core element of consumer-directed programs. States vary in the methodologies they employ to determine individual budgets but are federally obliged to ensure that the method is data-based and used consistently across the state.
* Common methodologies to calculate individual budgets include the use of historical cost and service utilisation data or the use of more sophisticated mathematical formula models.
* Mathematical formula models may derive Individual-based Budget Allocations (IBAs), where each individual is allocated a unique budget, or Level-based Budget Allocations (LBAs), where individuals are assigned to a level of allocation, albeit with finer distinctions within each level.
* The DOORS project in Wyoming and ReBar project in Oregon provide useful examples of IBA and LBA models.
* State licensed or certified disability providers are federally obliged to employ standard reimbursement rates for services. These rates must be transparent to potential service users and must be itemised in considerable detail for billing purposes. Bills are typically paid by a brokerage service to the provider on instruction from the budget holder.
* Federal requirements for data-based methods to determine individual budgets have led many states to use standardised and psychometrically tested measures of support need.
* A comprehensive comparison of a number of support need assessments found that the Supports Intensity Scale (SIS) was the most robust. The SIS has widespread use both within the US and internationally.
* While traditionally available to those with developmental disabilities within the US, there is legal scope to expand consumer-directed options to others, in particular, to those with mental health difficulties and to veterans, both of whom have expressed interest in this model of service delivery.

# 4. Allocating Resources on the Basis of Individual Support Needs

## 4.1 Rationale for introducing a system-wide resource allocation system based on individual support needs

There are multiple benefits to the proposal to transform the current resource allocation system of disability services in Ireland from a traditional block funding arrangement to an alternative system whereby individuals are assigned a personal allocation of funding based on their specific support needs.

First and foremost, from an equity perspective, individual budgets aim to ensure that resources are allocated depending on individual need. The current block funding system has been found to be inequitable on a number of grounds. NDA, for example, has presented data to the Value for Money and Policy Review of Disability Services illustrating how the per-person cost of services in Ireland is unrelated to level of support need[[240]](#footnote-240). Individuals with greater levels of need are therefore not automatically guaranteed greater levels of support. The distribution of current disability funding, in fact, varies not by level of individual need but rather by geographical region and by service provider, a situation described by the Comptroller and Auditor General as ‘perpetuating existing inequalities’[[241]](#footnote-241). An equitable system would ensure that, irrespective of where people live or who provides their support, the determination of their funding allocation is based on their level of individual support need.

Individual resource allocations also enhance equity through their recognition of the contribution of caregivers when determining an individual allocation[[242]](#footnote-242). An equitable system should consider the current level of support a person receives from natural supports, such as family, friends or others within their local community, and should be cognisant of whether this level of support is reasonably and willingly provided by these unpaid caregivers[[243]](#footnote-243). Individual allocations should appropriately reflect the level of caregiver support provided to an individual by ensuring that those who have minimal or no access to natural supports are appropriately resourced to meet their needs.

The introduction of individual budgets at system-wide level will also be a necessary and welcomed initiative for those wishing to exercise greater control in developing and implementing their own support package. The transition from a professionally-led assessment system to a self-assessment or supported assessment system will empower people with disabilities to play a central role in assessing, planning and monitoring their own support needs[[244]](#footnote-244). Because the funding is attached to the person, and not to the provider organisation, individuals can design their support package in a way of their choosing, secure in the knowledge that the "money follows the person". Individuals who are dissatisfied with their supports will be able to change provider, an option that is likely to make provider organisations more accountable in the services they provide. In addition, more inclusive options will be available to individuals who choose to arrange their support packages from generic or mainstream sources, rather than solely from traditional disability providers[[245]](#footnote-245).

From a transparency perspective, individual budgets provide considerably more clarity than block funding as to precisely how and where public funds are spent. An assessment-informed method for determining individual budgets is reliant on ongoing and updated data from both sides of the allocation algorithm; that is, in terms of reliable and standardised assessments of support need on the one hand, and in terms of reasonable and appropriate reimbursement rates for support services on the other[[246]](#footnote-246). In relation to the former, a system-wide standardised assessment of need would provide greater clarity for consumers than the current array of professionally-led and highly clinical assessments. In the UK, for example, some local councils present their needs assessment forms online[[247]](#footnote-247), [[248]](#footnote-248),[[249]](#footnote-249), thereby providing complete transparency to consumers on the content of their assessment. In relation to the service cost side of the equation, the US system provides transparency to stakeholders by requiring standard reimbursement rates to be applied statewide and, where this is not the case, changes from authorised rates must be communicated to budget holders[[250]](#footnote-250). Service reimbursement rates must be made publicly available, usually via states’ Department of Human Services’ websites[[251]](#footnote-251). This public availability of service reimbursement rates ensures a transparency of costs to potential consumers, service providers, policy makers and other stakeholders.

From a perspective of cost, individualised systems of resource allocation in other jurisdictions have generally been found to achieve cost savings while providing substantial improvements in quality outcomes. Given the current financial pressures both nationally and internationally, more targeted and efficient use of diminishing resources is to be welcomed[[252]](#footnote-252). Early evaluative data from the UK suggested cost savings in the order of 9% where In Control’s self-direction had been implemented[[253]](#footnote-253). These findings have been mirrored elsewhere throughout the UK, in particular a review of ten local councils reported savings of 10% between traditional and self-directed services[[254]](#footnote-254). Savings reported from the pioneering self-determination projects supported by the Robert Wood Johnson Foundation in the US ranged 12% to 15%[[255]](#footnote-255). Similar findings were reported from evaluations of the implementation of self-directed services in Michigan, where average costs decreased 16%, albeit not uniformly across all participants[[256]](#footnote-256). The cost findings are, however, not entirely uniform, with some studies reporting no significant differences in costs between traditional and self-directed services[[257]](#footnote-257), and others reporting considerable cost savings based on very small sample sizes[[258]](#footnote-258). Acknowledging the variability of quality in costing studies in this field, a recent review conducted by the Productivity Commission of Australia concludes ‘there is enough evidence from diverse sources to suggest that self-directed funding is likely to be less costly than alternative service models’ (Appendix E, p.19)[[259]](#footnote-259). The report cites anecdotal evidence from US studies indicating that these savings arose from a reduction in pressure for consumers to use unwanted services, the selection of services that best meet personal need, the negotiation of lower costs with providers and the transfer of administration activities from providers to budget holders[[260]](#footnote-260). Notwithstanding the growing evidence of cost savings following the introduction of individual budgets and self-directed services, commentators are now voicing the possibility that these direct financial savings may in fact be considerably less than potential longer-term indirect savings on the basis that people who self-direct are less likely to use long-term care supports or crisis hospital stays[[261]](#footnote-261).

All the benefits reviewed above, whether from an equity, transparency or cost saving basis, must be placed within the context of outcomes for people with disabilities. Ultimately, any system should result in quality outcomes. Findings to date suggest that the introduction of individual budgets and self-directed services is associated with quality outcomes, not only for consumers[[262]](#footnote-262), but also for their families[[263]](#footnote-263). This finding, in conjunction with those benefits outlined above, provide a compelling argument for the introduction of a resource allocation model based on individual support need.

## 4.2 The Supports Model

Of the myriad of reasons in favour of an allocation system based on individual need, it is the inherent inequity of traditional block funding models that has been a major driver in the transition to allocations based on individual support need. Essentially people with the least needs should be allocated the least amount, while those with greater needs should receive more[[264]](#footnote-264).

Historically, people with disabilities have been classified according to diagnostic classifications such as 'intellectual disability', 'visual impairment' or 'cerebral palsy'. Having been classified with a particular diagnosis, the individual was referred to specialist disability services predicated on programme models that specifically met the needs of those so classified. This traditional model is deemed to potentially place some individuals in settings that they do not need while at the same time leaving some individuals' needs neglected[[265]](#footnote-265). And yet, eligibility for service provision largely remains determined by diagnostic categories resulting in many people with disabilities feeling that they must fit into available programmes[[266]](#footnote-266).

A change in the classification of persons with intellectual disabilities by the then titled American Association on Mental Retardation[[267]](#footnote-267) (now the American Association on Intellectual and Developmental Disabilities; AAIDD) caused a paradigm shift that has had far reaching consequences for people with disabilities across the globe. The definition of intellectual disability retained reference to IQ, co-existing limitations in adaptive behaviour and onset prior to 18 years, but controversially altered the classification system from one which classified by level of IQ, to one which classified by intensities of supports; according to settings in which supports are needed, the resources required for the supports, the time-duration and time-frequency of supports, and the degree of intrusiveness[[268]](#footnote-268). This alteration in classification shifted the goal of assessment from that of determining an individual's eligibility to receive services according to disability level, to that of reducing the mismatch between environmental demands and individuals' capabilities[[269]](#footnote-269).

While definitions vary, a well-established definition identifies supports as "resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning"[[270]](#footnote-270). Although this definition was developed within the specific context of people with intellectual disability, it is acknowledged that the concept is applicable for all individuals, albeit that those with disabilities may require different types and intensities of supports[[271]](#footnote-271). Supports can be perceived as a 'bridge' between the individual's present state of functioning, and a desired state of functioning. While a key goal of the provision of supports to people with disabilities is to enable people to function in 'typical life activities in mainstream settings', attempts to enhance functioning through the provision of supports should not be conceived as an attempt to 'fix' or 'compensate' for limitations. Rather, improving the life situation of an individual with a disability requires individual planning of supports based on personal preferences as well as available resources[[272]](#footnote-272).

The impact of the supports paradigm shift has substantially altered professional practices within the disabilities field. Assessment of support need has become a basis for individual planning and the intensity of support is now used internationally as a basis for system planning and resource allocation[[273]](#footnote-273),[[274]](#footnote-274). Indeed, the support paradigm is credited with stimulating debate internationally regarding the equitable allocation of funding and resources within disability services[[275]](#footnote-275). As greater demands are placed on diminishing resources, organisations providing services to people with disabilities seek more robust and equitable systems as a basis for planning and reimbursement[[276]](#footnote-276). The development of individualised funding models based on individual support needs is deemed to offer a rational and equitable allocation of public funds[[277]](#footnote-277) and is now identified as a core feature of contemporary disability services[[278]](#footnote-278).

The AAIDD support model provides a useful template of the process of assessing, planning and monitoring individualised support need. The model provides an overall framework within which individual funding allocations are typically determined. The process begins with a detailed consultation to determine the individual's personal preferences and interests. Person-centred planning (PCP) is recommended as the optimal method of eliciting these preferences and interests. A second step is the assessment of the individual's support needs. These assessments may be undertaken by self-report or by objective indicators of the intensity of support required. A variety of methodologies can be used including standardised assessment, interview or direct observation[[279]](#footnote-279). The outcome of the assessment should be an indication of the support needs an individual requires, especially those supports associated with key priorities identified in the planning stage. The emphasis throughout the assessment should be firmly placed on the individual's support needs and not on the individual's competencies, that is, on the supports an individual requires to achieve a particular outcome rather than on any perceived limitations an individual may experience due to disability.

Building on these first two steps, an Individual Plan is then developed. The plan should identify specific and individualised outcomes that the individual wishes to achieve over a given time period. The fourth step in the support model is monitoring the implementation of the plan in an ongoing and systematic manner. Finally, the concluding step is an evaluation of whether the individual's personal outcomes have been realised. Aggregate data on the achievement of personal outcomes is an important indicator for providers and state systems in determining whether services are meeting the needs of individuals[[280]](#footnote-280).

|  |  |
| --- | --- |
| Table 3: A process for assessing, planning, monitoring and evaluating individualised supports **(Thompson et al., 2009)[[281]](#footnote-281).** | |
| **Component 1:**  Identify Desired Life Experiences and Goals (PCP) | **Component 2:**  Assess Support Needs |
| **Component 3:** Develop and Implement the Individualised Plan  (use results from 1 and 2 to prioritise preferences and identify personal outcomes and needed supports - identify supports that are needed and that are currently used - develop an individual plan) | |
| **Component 4:** Monitor Progress  (monitor the extent to which the plan was implemented) | |
| **Component 5:** Evaluation  (evaluate the extent to which personal outcomes have been enhanced) | |

## 4.3 Calculating an individual funding allocation based on support need

Individualised funding is defined as 'resources that are allocated based on needs which are identified through the planning process, to support the design and identification of supports that are flexible and responsive to individual needs'[[282]](#footnote-282). Individualised allocations may cover the cost of all or part of the services an individual is authorised to receive, and should provide the individual with the authority to use the fund to purchase services and supports consistent with his or her support plan[[283]](#footnote-283). The allocations should be determined on the basis of individual assessments of needs and should provide sufficient flexibility to allow for adjustment in the event of a change to the individual's support needs or service plan[[284]](#footnote-284).

Irrespective of the specific methodology employed to calculate budgets based on individual support needs, most models can be classified as either 'prospective' or 'retrospective' in nature[[285]](#footnote-285). The difference is essentially the stage at which, in the process of assessing, planning and monitoring, an individual's budget allocation is determined. Prospective methods determine individuals' funding allocations prior to the development of their support plan; that is, individuals know how much funds will be available to them before they develop their support package. These methods utilise statistical modelling to determine the contribution of an array of variables in predicting the level of funding required to meet need. Generally, the models are constructed using data from representative samples of individuals on variables that are deemed to influence cost including level of support needed, service utilisation, demographics, geographic location, and local economic factors. Mathematical formulae are then used to determine the predictive relationship between these variables and cost, and for this reason these methods may also be known as 'statistical models'[[286]](#footnote-286). Models such as the In Control RAS, the DOORS project in Wyoming, and the ReBar project in Oregon all employ a prospective design in the construction of the resource model. It is important to note that while prospective models have the advantage of ensuring that existing resources are fairly and equitably distributed, the cost data are based on overall fixed funding amounts and as such the sufficiency of each individual's allocation is dependent on the size and proportional adequacy of the overall existing fund[[287]](#footnote-287).

Retrospective approaches, in contrast, use an open-ended and subjective process to determine individualised funding allocations. Retrospective models calculate the funding allocation during the planning process using person centred planning. The state of New Hampshire, for example, uses a retrospective methodology whereby an Individualised Service Plan (ISP) is agreed between the individual (and family) and an Account Manager[[288]](#footnote-288). The ISP identifies the individual's selection of supports from those presented by the Account Manager, and the agreed support package is then costed, typically using a hourly fee-for-service reimbursement rate[[289]](#footnote-289). In New Hampshire, the total cost of the individual's allocation is classified into three components; the direct cost of support, a 10% general management fee, and a service fee for case management. The Account Manager provides ongoing support with budget management and produces monthly update reports. In contrast to the prospective methodology outlined above, retrospective models do provide sufficient funding allocation to meet an individual's need. Retrospective models do not, however, ensure that the overall fixed funding amount is allocated equitably across all those requiring supports. That is, where resources are low, those who receive an allocation sufficient to meet their needs may receive larger proportions of the overall fixed funding amount than would be provided under a prospective methodology. This methodology may thus inadvertently leave insufficient funds for others of similar need; a situation which can result in extensive waiting lists for services[[290]](#footnote-290).

Of the two types of models, the prospective methodology is dominant in both the US and the UK. The Centers for Medicare and Medicaid Services, for example, define the term individual budget amount as a 'prospectively' determined amount of funds the state makes available for the provision of waiver services to an individual'[[291]](#footnote-291). Similarly, throughout the UK local councils are advised to inform individuals of their indicative personal budget at an early stage of the self-directing process[[292]](#footnote-292).

**Prospective and Retrospective Budgeting Approaches**

**Person Enters System**

**Service Needs Assessment**

**Determine Total Funding Amount**

**Complete PCP**

**Retrospective**

**Prospective**

**Complete PCP**

**Determine Total Funding Amount**

**Services to Support PCP Goals**

Table is presented with kind permission of Charles R. Moseley: from Moseley, C., (2008). State Resource Allocation Strategies and Challenges. Presentation to Maryland Developmental Disabilities Administration, January 14th, 2008.

Whether prospective or retrospective in nature, an emerging consensus has developed regarding the core characteristics of individual funding methodologies. In addition to being logical, reasonable and easily understood, methodologies should comprise the following 'essential' elements:[[293]](#footnote-293),[[294]](#footnote-294)

|  |  |
| --- | --- |
| Table 4: Essential Elements of Determining Individualised Funding Allocations **(Crisp et al., 2010)[[295]](#footnote-295)** | |
| Accurate | Methods should reflect valid assessments and provide sufficientfunding amounts to meet individual need. |
| Consistent | Methods should be applied consistently across programmes, locations and individuals. |
| Reliable | Methods should produce consistent results over time when repeated. |
| Equitable | Methods should ensure that those with similar need and circumstances receive similar amounts - both for those in traditional services and those who wish to self-direct (assuming comparable need) - a fair relationship must exist between the cost of traditional services and the individual's self-directed budget. |
| Flexible | Methods should permit changes to the budget to be made easily and in a timely fashion to accommodate changes in the individual's circumstances or choice. |
| Transparent | Methods should be open to public inspection. |

## 4.4 Assessments of individual support need used in the determination of individual budgets

The selection of an appropriate assessment of individualised support need is an important consideration in meeting the criteria outlined above. While de novo tools may at first glance appear to meet local need, their lack of psychometric validity may render them an unsuitable choice for attaining the requirements of accuracy, consistency, reliability, equity, flexibility and transparency across a large population group. In contrast, standardised measures of support need, while perhaps not initially developed for the purposes of resource allocation, are likely to provide a more robust measure from which budgets can be determined[[296]](#footnote-296).

A total of three measures shall be reviewed briefly as potential options for use in determining individual budgets at nationwide level in Ireland. While there are a multitude of support needs assessment tools available, these measures were selected on the basis that they have previously been used within the context of determining individual budgets for people with disabilities; have been developed with the potential for use at national level; have robust psychometric properties; and are appropriate for use with persons with a range of disabilities. In fact, while each of the three measures endorsed some of these criteria, none achieved success across all criteria. There are, as such, pros and cons to each measure.

These three comprise:

* In Control RAS 5
* Support Intensity Scale (SIS)
* Instrument for the Classification and Assessment of Support Need (I-CAN)

### 4.41 In Control RAS 5

In Control is a UK national charity established in 2003. In Control began its work by illustrating how the social care system in England could be reformed using self-directed support. In Control's mission statement is 'to create a fairer society where everyone needing additional support has the right, responsibility and freedom to control that support'[[297]](#footnote-297).

In Control has devised a seven stage process of self-direction whereby individuals

* find out how much money they will receive for their supports
* plan their own supports
* get their plan agreed by a funding body
* organise how their money will be managed with a level of choice at their discretion
* decide how their supports will be arranged
* implement self-direction and
* monitor their supports and adapt as appropriate[[298]](#footnote-298).

In Control's system of self-directed support is credited with introducing the concept of a personal budget within the UK social care system and is now in widespread use throughout local councils in England. From an initial 60 persons using personal budgets in 2006, the number had risen to 30,000 people across 75 local authorities by 2009. Of those in receipt of a personal budget, over half were older people, almost one quarter people with a physical disability, almost one in five people with an intellectual disability, and 6% people with mental health difficulties[[299]](#footnote-299). The In Control model thus reaches the criteria set out above of being used within the context of determining personal budgets, being national in scope, and being applied to persons with a wide range of disabilities.

In Control's resource allocation system, the RAS, informs individuals of how much funding they can reasonably expect to be made available in their personal budget; an amount termed an 'indicative' allocation. The aim of RAS is to allocate appropriate levels of resources to individuals who require support according to their needs and circumstances, that is, ensuring those with similar needs, in similar situations, receive similar supports. In addition to determining an indicative personal budget, RAS identifies the outcomes that the supports must be used to achieve. In fact, self-directed support as promoted by In Control, emphasises the personal outcomes individuals achieve rather than the determination of funding they receive[[300]](#footnote-300).

In Control's RAS is based on a self-assessment questionnaire (SAQ) which assesses the impact of people's disability on their lives. An example of an SAQ is presented in Appendix A[[301]](#footnote-301). The SAQ marks a distinct development away from the highly complex and professionally-led assessment processes previously conducted in adult social care in England. First and foremost, the SAQ is a self-assessment measure as opposed to a professionally completed assessment. Secondly, the SAQ is firmly rooted in eliciting personal outcomes of support required in everyday life, such as a person’s desire for increased choice and control over decisions, rather than eliciting the available services a person might require, such as a need for respite, which is the focus of more traditional assessments[[302]](#footnote-302).

In Control's SAQ varies somewhat depending on local need, however the typical domains examined include

* Meeting Personal Care Needs
* Eating and Drinking
* Practical Aspects of Daily Living
* Physical and Mental Wellbeing
* Relationships and Social Inclusion
* Choice and Control
* Staying Safe and Taking Risks
* Work and Learning
* Support from Friends, Family and Community
* Family/Carer Role and
* Complex Needs and Risks.

Each domain incorporates an outcome such as 'to be clean and dressed' within the Meeting Personal Care Needs domain, or 'to be able to access my community' within the Relationships and Social Inclusion domain. Each domain comprises a number of statements, each of which has a point allocation if endorsed. Under the Eating and Drinking domain, for example, four statements are presented ranging from 'I need lots of help to eat and drink' which is allocated 15 points, to 'I do not need help in this area' which awards zero points. In between these points is ‘I need help and encouragement to eat and drink’ which is allocated 7 points and ‘I need all my meals to be provided or prepared for me’ which is allotted 3 points. As such, higher points are awarded for greater need.

An individual's responses to all items are collated and the person's total point allocation is multiplied by a local 'price point'. The monetary amount of a price point is worked out by each local council at the initial stages of implementing a resource allocation system, on the basis of locally determined funding levels. Each level of funding is based on local intelligence from a desk exercise whereby the current spending of a representative sample of approximately 100 real cases of persons achieving agreed outcomes are determined. Information on the needs assessment scores and the costs of support are therefore available for each percentile of the population[[303]](#footnote-303),[[304]](#footnote-304). In Control state that the emphasis on agreed outcomes and the strong links to local costs and systems makes the RAS a robust and equitable system[[305]](#footnote-305).

To date, five versions of RAS have been developed. The latest version, termed 'RAS 5' was developed in 2007 by John Waters, In Control's Technical Director and is also known as e-RAS. RAS 5 has been used extensively throughout England, most notably due to its endorsement by the Association of Directors of Adult Social Services (ADASS) as a template RAS for their Common Resource Allocation Framework[[306]](#footnote-306). In Control state that the key innovation of this fifth version is that it is no longer reliant on setting personal budgets by reference to the cost profile of the past, that is, the 100 locally-based individuals in receipt of social care. Given that these data are gathered as a first step in the development of the resource allocation model, the cost profile of this sample will be based on historical service models. As more and more individuals move towards self-directed services, however, the RAS becomes populated by cost data from the field, by those who are self-directing. By definition, these latter costs, now available in RAS 5, are a more accurate predictor of the cost of self-directed services than those determined from traditional service models[[307]](#footnote-307).

An allocation table is created by aligning the SAQ scores from each percentile in the sample with the support costs incurred by individuals at that percentile. That is, if 10% of the sample scores at or below 18 points on the SAQ, and if 10% of the sample incurs costs at or below £2,876, then a total score of 18 points is afforded a budget of £2,876. In this manner, the allocation table presents the respective costs for each percentile of the sample. The allocation table will certainly redistribute finances differently to the system it replaces and monitoring is essential to ensure that people are able to meet their needs on their new allocation. Given that calibration of the model is a likely requirement as the model develops, an initial contingency factor set between 5-25% is recommended[[308]](#footnote-308),[[309]](#footnote-309). ADASS advise that local councils will always need to exercise some discretion in deciding the amount of a personal budget'[[310]](#footnote-310).

It is important to note that RAS provides an indicative personal budget. The final amount of the personal budget is decided only at the point when the individual's support plan is agreed. The support plan should outline clearly how the individual will achieve the agreed outcomes, and should detail the actual cost of providing the supports necessary to achieve those outcomes. In Control recommend that this process be kept as flexible and simple as possible in an effort to avoid over-complication and professionalism. Brokerage, local area coordination models[[311]](#footnote-311), Citizen's Advice Bureaus, and Centres for Independent Living all provide resources to assist individuals to maximise the use of their budget to meet individual need. An initiative which is identified by In Control as a best practice model in supporting individuals utilise their personal budget in an informed manner is the shop4support website operated by the London Borough of Harrow[[312]](#footnote-312). Shop4support showcases an array of service option supports alongside their respective costs which are further broken-down as costs attributable to the individual, the service provider and/or the local council. The website reflects the In Control philosophy of avoiding overly complicated and professionally driven services.

The In Control model has undertaken three evaluations to date, (first 2003-2005, second 2005-2007 and third 2008-2009). Findings indicate that quality of life for those self-directing their own services is enhanced, while the cost of supports is reduced by 9% from traditional service models[[313]](#footnote-313). In Control argue that better quality supports do not require increased funding because people often know best how to meet their own needs, especially in consultation with their friends and family. Traditional services do not meet the needs of individuals who prefer to spend their money on services that keep them connected within a society and for which they themselves are accountable[[314]](#footnote-314). The psychometric standing of the RAS 5, however, and its predictive ability to determine cost has not been extensively tested. Rather, the evaluations have focused on the quality outcomes gained by those who have selected to self-direct their own services. This lack of formal scientific data has led to some criticism as to whether a single 'price per point' system across the varying and heterogeneous group that comprise adult social care recipients is appropriate[[315]](#footnote-315). For those who advocate the In Control model, however, the narrow scientific focus on the predictive regression coefficient from a multi-variant analysis misses the point[[316]](#footnote-316). Rather, the focus is firmly on whether the outcomes generated by individuals in their support plans have been achieved. Furthermore, the fact that the model is rolling out as a nationwide system across the UK speaks for itself.

Without doubt, the In Control philosophy has radically altered the landscape of adult social care within England. Future developments for In Control include the continuing roll out of the model throughout the UK, the further development of a children's version following from the Taking Control pilot (where Budget Holding Lead Professionals are charged with managing children's budgets[[317]](#footnote-317)), and the expansion of the model in international jurisdictions. In Control now operates in Scotland, Wales, Australia, New Zealand, Tasmania, the Czech Republic, the USA, Italy, Russia and Finland. In Control is also in the early stages of being piloted in Ireland by KARE, an intellectual disability provider in the Kildare region. To date, twenty-four adults with intellectual disabilities have begun to self-direct their own services rather than avail of the traditional services on offer. Simultaneously, KARE is conducting research on the unit costs of services it provides[[318]](#footnote-318).

In terms of the potential use of the In Control RAS as a national resource allocation system here in Ireland, the model may be deemed to reach three of the four criteria outlined above; it has been used within the context of determining individual budgets for people with disabilities, it has extensive use at national level, and it has, albeit with some criticism, been used widely across a range of persons in receipt of social care supports. The RAS 5 does not, however, have the volume of psychometric data that is available with other similar tools. As explained above, this may be more a reflection of the In Control philosophy than an indicator of any lack of validity of the tool. The absence of such data does not equate to a statement of invalidity of the tool, merely that such data are not in the public domain. In fact, these data may be available within the many local councils who are charged directly with developing their resource allocation models, and where evaluative reviews are underway[[319]](#footnote-319). It would be advantageous for Ireland to undertake similar work should the model be introduced in this jurisdiction.

### 4.42 Support Intensity Scale (SIS)

The Supports Intensity Scale (SIS) was developed over a five-year period by the American Association on Intellectual and Developmental Disabilities to assist disability organisations understand the support needs of people with intellectual and related developmental disabilities[[320]](#footnote-320). The SIS was developed within the context of a changing perspective of people with intellectual and developmental disabilities from one which emphasised a person's deficits in adaptive behaviours and independent living skills, to one which emphasised how individuals could live a life of their choosing with appropriate supports. The movement was summarised by the phrase 'people who have a life and need support'[[321]](#footnote-321). This changing perspective, leading to consumer-directed and individualised services provided the impetus for the development of a standardised, valid and reliable measure of individual support need, the Supports Intensity Scale (SIS).

SIS is heralded as the measure of choice among states and governments who aim to understand and analyse the service needs of persons with intellectual disabilities[[322]](#footnote-322). It comes with a considerable psychometric pedigree having been normed on a sample of 1,306 people resident in 33 states across the US. Psychometric data on reliability and validity of the SIS are available in the peer-reviewed literature[[323]](#footnote-323),[[324]](#footnote-324),[[325]](#footnote-325),[[326]](#footnote-326). SIS is now in use in 14 states throughout the US[[327]](#footnote-327), and is available in 13 languages in 19 countries[[328]](#footnote-328),[[329]](#footnote-329). Psychometric validations of the SIS in other languages include French[[330]](#footnote-330),[[331]](#footnote-331) Dutch[[332]](#footnote-332),[[333]](#footnote-333) and Spanish[[334]](#footnote-334),[[335]](#footnote-335). The SIS undoubtedly meets the criteria set out above of being developed with the potential for use at national as opposed to local level, and having robust psychometric properties.

The SIS is copyrighted to the AAIDD and for that reason it cannot be presented in this report. A brief overview of the three sections it comprises is provided below based on material that is publicly available. Section 1, the Support Needs Scale comprises 49 life activities across six domains:

* home living,
* community living,
* lifelong learning,
* employment,
* health and safety, and
* social activities.

Scores from this section provide two indices of support needs. The SIS Support Needs Index provides a composite score that reflects a person's overall intensity of support needs relative to others with developmental disabilities. The Support Needs Profile is a graphic plot that provides a visual graph or pattern of a person's support needs across all six life activity domains. These scales should be completed without regard to the services currently available to the respondent and should be completed irrespective of whether the person currently engages in the activity being measured. For each item, respondents must determine how frequently support is needed for the person to engage in the activity, how much time is required to give support in this area on a typical day, and what kind of support is provided. The frequency of support, support time and type of support scores are then collated for each item, and for each domain. Normative tables based on the data gathered from 1,306 people resident in 33 states across the US are available to transform each respondent’s raw scores to standard scores and percentiles. These normative scores are used to interpret individual scores, e.g. scoring at the 70th percentile means that the respondent has scored equally or higher than 70% of the normative group.

Section 2, the Supplemental Protection and Advocacy Scale measures eight activities. The scores from this section are typically used in developing individualised support plans and are not used to determine either of the support needs indices mentioned above. The types of items explored in this area include protection from exploitation, exercising legal responsibilities, and making choices and decisions. They are rated using the same criteria as Section 1, in terms of frequency, support time and type of support.

Section 3, Exceptional Medical and Behavioural Support Needs, measures support needs across 15 medical conditions and 12 problem behaviours. These areas are given specific coverage on the assumption that they are predictors of high support need. The key issue to address is the significance of the medical condition or behavioural need with regard to extra support required. Items within Exceptional Medical Support Needs examine the use of personal assistance or equipment to manage medical conditions. Items within the Exceptional Behavioural Support Needs address the severity of behaviours that are deemed inappropriate. A common scoring frame is employed across both the medical and behavioural items, ranging from 'no supports needed' to 'extensive support needed'.

While the Supports Intensity Scale was developed primarily as a tool for individual support planning, applications for its aggregated data have received considerable interest[[336]](#footnote-336). As a first step, aggregated SIS data plotted by individuals' existing annual funding allocations provide illuminating data to service providers and funding bodies as to the relationship between support need and cost. Where the relationship is weak, further investigation is required to determine if the individual's allocation is deemed an over- or underestimate. Variation in individual cost is to be expected and an array of variables such as geographical location, economic climate and service utilisation, in addition to individual support need, contribute to this variation. Attempts to identify these predictors of costs during the field testing of the SIS, based on 575 individuals with developmental disabilities, revealed that up to 68% of costs could be predicted using a combination of variables including residential setting (32%), SIS scores (29%) and presence of psychiatric disorder (7%)[[337]](#footnote-337). Further studies have revealed that the predictive power of these models varies considerably by jurisdiction and have been reported to range from 26% to 81% in different regions[[338]](#footnote-338).

When used within the context of resource allocation, two applications for SIS dominate, the determination of a prospective budget amount that represents an upper limit on the total amount of funding that is authorised to purchase goods and services on a person's behalf, and service payments, that is, the determination of provider payments for the delivery of specific services[[339]](#footnote-339). The Human Services Research Institute (HSRI) has considerable experience within the US and elsewhere utilising the SIS for the purposes of determining prospective budget amounts and service payments, often within the context of Medicaid HCBS funded state services[[340]](#footnote-340). While there are variations in the application of SIS for this purpose, the example below provides an indication of the potential of SIS within this field. Typically, a pilot sample of approximately 500 individuals within the target group (such as those in receipt of a given Medicaid waiver) completes the SIS. In due course, the SIS is administered to each member of the full population of interest. Each assessment is led by an assessor, usually the person's case manager who should undertake extensive training from AAIDD. Guidelines recommend that all persons administering the SIS must meet AAIDD Interviewer Reliability Review criteria[[341]](#footnote-341). Throughout the assessment, the individual is accompanied by two persons who know the person well, typically a family member or a staff member from a disability provider organisation[[342]](#footnote-342). For the purposes of resource allocation, additional data is also obtained per participant such as expenditure on billings and paid claims from state mainframe data systems, information on living arrangements, risk assessment data etc.

These data are combined using statistical modelling whereby patterns among variables that are found to predict service costs are observed. These patterns identify groupings of participants who share similar characteristics. These groupings are termed 'assessment levels'. Typically, several iterations of this process are undertaken to further refine these levels using adjustments for behavioural and medical needs. The analysis to assign persons to respective levels typically involves four steps. Firstly, the observed SIS scores are compared against the normative data. The closer these data align, the greater the level of confidence in the SIS model. Secondly, an analysis is undertaken to identify factors, including the SIS, that explain variations in the historical expenditure of participants. These models produce a regression coefficient, which is essentially the percentage of variation in costs that can be predicted from an array of variables including support need[[343]](#footnote-343). The higher the regression coefficient, the better the model is at predicting cost. Thirdly, discrete reimbursement levels are created. Key decisions are required by stakeholders on the development of these levels such as whether they will be budget neutral, what the maximum number of levels will be and what funding schemes they apply to. Finally, the reimbursement levels are applied to the full population. This is achieved by arraying the average per diem payment associated with each subgroup and dividing by the number of levels, producing a level which is populated by subgroups with similar average payment amounts. A minimum of 10% of the population should populate each level. Initially, the levels may not align well with current payments, on the basis that current payments are typically not related to support need due to the historical nature of the funding. As the model becomes populated with more recent expenditure, the relationship becomes stronger[[344]](#footnote-344). There are six commonly used levels for residential supports ranging from Support Level 1, for persons classified as requiring weekly or less support, to Support Level 6 for those with extensive behavioural support needs[[345]](#footnote-345). The six residential levels are presented in the table below. Typically, the majority of people with intellectual disabilities in a given jurisdiction will be appropriately classified within such a model. It is likely, however, that those with severe and complicated disabilities (which may range anywhere from 7% to 76% depending on the population being examined) will not be covered by the SIS model[[346]](#footnote-346).

The SIS is currently being trialled in Ireland by the Saint John of God Services using a model developed by Washington State’s Division of Developmental Disabilities[[347]](#footnote-347),[[348]](#footnote-348). This pilot initiative has determined within-service allocation costs for a group of 102 residents at Menni Services. Within-service allocation costs refers to the use of the SIS to determine a cost for people within a given service unit, (in this case residential settings within Menni Services), with a view to equitably allocating the available resources within that service. To date, a support dependent cost has been determined for each individual. These costs are based on the total costs of providing the service, minus the 'stable' costs which essentially comprise the non-pay costs and once-off capital expenses, such as transport, overheads, material costs, housing etc. Residents have now been assigned to respective levels. Currently the project is in the process of determining a Residential Service Rate Model, that is, a rate that can be prospectively negotiated with a funding body. To achieve this, an estimate will be determined of the number of hours support required across various life domains using SIS data from the 102 participants; this information will be used to determine the base hour rate for each domain. Base hours represent the average support time required in each life area for people who respond similarly on the SIS. The model will require flexibility to permit adjustments to the predicted costs for individuals, for example, in cases of unusual circumstances where a typical allocation would not be sufficient. The project is currently immersed in the process of refining its model with a view to establishing a community services base model and standardised rates for support packages. There is much to be learned from this pilot initiative, not only in terms of the potential of the SIS tool, but more broadly in terms of the issues raised by the introduction of resource allocation models across a host of areas including service arrays, finance, and human resources. The SIS is also in the initial stages of being implemented in the Carlow, Kilkenny region. This project, initiated by the HSE involves the participation of a number of intellectual disability provider organisations in the region piloting the SIS as a support needs measure. HSE has funded an intensive week long training of assessors by AAIDD which took place in March 2011. While the primary aim of this project is the development of a support needs model, as opposed to the development of individual budgets, there will be valuable learning from this initiative[[349]](#footnote-349).

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| Table 5: Residential Service Levels of Support Based on SIS Scoring**[[350]](#footnote-350)** | |
| Weekly or less (Support Level 1) | Requires supervision, training or physical assistance in areas that typically occur weekly or less often, such as shopping, paying bills, or medical appointments. Generally independent in support areas that typically occur daily or every couple of days. |
| Multiple times per week (Support Level 2) | Is able to maintain health and safety for a full day or more at a time AND needs supervision, training, or physical assistance with tasks that typically occur every few days, such as light housekeeping, menu planning, or guidance and support with relationships. Generally independent in support areas that must occur daily. |
| Intermittent daily - low (Support Level 3A) | Is able to maintain health and safety for short periods of time (hours but not days) OR needs supervision, training, or physical assistance with activities that typically occur daily, such as bathing, dressing or taking medications. |
| Intermittent daily - moderate (Support Level 3B) | Requires supervision, training, or physical assistance with multiple tasks that typically occur daily OR requires frequent checks for health and safety or due to disruption in routine. |
| Close proximity (Support Level 4) | Requires support with a large number of activities that typically occur daily OR is able to maintain health and safety for very short periods of time (less than 2 hours, if at all) AND requires occasional health and safety checks or support during night time hours. |
| Continuous day + continuous night (Support Level 5) | Is generally unable to maintain health and safety OR requires support with a large number of activities that occur daily or almost everyday AND typically requires night time staff continuously in the home. |
| Community protection (Support Level 6) | Is enrolled in the Community Protection Programme. |

To conclude, there seems little doubt that the SIS reaches three of the four criteria set out above, that is, having been used within the context of determining individual budgets, being developed with the potential for use at national level, and having robust psychometric properties. It is the criterion regarding the applicability of the tool for use with a wide range of persons with disabilities that potentially limits the use of the SIS. Despite some initial work in this regard[[351]](#footnote-351),[[352]](#footnote-352), the SIS has yet to be used in an applied setting with persons with a range of disabilities, rather it remains rooted within the field of intellectual and developmental disabilities. The suitability of the scale items, and the normative data, may have to be reviewed if the measure is to be expanded to those with other disabilities, such as physical or sensory disabilities, or those with mental health difficulties.

### 4.43 Instrument for the Classification and Assessment of Support Need (I-CAN)

In 1998, the Centre for Developmental Disability Studies (CDDS; later renamed the Centre for Disability Studies) at the University of Sydney engaged in a collaborative project with the Australian Capital Territory Community Care Disability Programme to develop an assessment tool that would validly measure the support needs of individuals with intellectual disabilities in community-based residential and respite settings[[353]](#footnote-353). Based on this early work, the Centre for Disability Studies received further funding from the Australian Research Council Linkage Project to develop the measure from an instrument designed initially to assess the support needs of those with intellectual disabilities, to a measure which would be applicable across persons of all disabilities[[354]](#footnote-354). The study, lasting from 2002-2004, tested the instrument on a sample of 1,012 persons with disabilities who were receiving either residential or day programmes from a total of sixteen different disability providers. The resulting instrument, the I-CAN, Instrument for the Classification and Assessment of Support Needs, has been validated as a support needs measure for persons with a range of disabilities[[355]](#footnote-355).

The I-CAN is based on the conceptual framework of support promoted by both AAIDD and the World Health Organisation (WHO). At the time of development of the measure, these two organisations had both reconfigured their classification system for persons with disabilities to reflect a less medical approach to disability. The amendments introduced by AAIDD have been outlined previously[[356]](#footnote-356). WHO similarly introduced comprehensive changes to their classification system of disability when, in 2001, they launched the International Classification of Functioning, Disability and Health (ICF). The ICF model reframes disability from its previous medical context to a bio-psycho-social context. ICF identifies the individual's functioning in everyday life as the product of a relationship between the person's health condition or impairment, the activities the person wishes to engage in, and the impact of environmental and personal factors on this engagement (e.g. discrimination, family background, physical environment, etc.) [[357]](#footnote-357). These two approaches to reframing disability form the basis of the I-CAN which focuses on the person, the supports the person requires, and the environmental factors which impact on the person’s participation in society. The model focuses on the interaction between individuals and their environment, via supports, which include both human relationships and technology. Table 6 presents the I-CAN model.

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| Table 6: The I-CAN proposed theoretical model of people, the support they need and the environment[[358]](#footnote-358). | | |
| Person | Supports | Environment |
| Personal Factors | People (family, friends, community members, staff, health professionals) education, technical aids, equipment, advocacy, industry, funding, transport. | Activities, Participation |
| Barriers, Facilitators, Limitation, Opportunity, Attitudes |
| Physical Health | Society, Culture |
| Built Environment, Natural Environment (pollution) |
| Mental Emotional Health | Political, Economic |
| Family, Friends |
| Technological |
| Behavioural Concerns | Historical |

Psychometric testing of the first three versions of the I-CAN was undertaken on a sample of 1,012 persons, most of whom had intellectual disabilities or multiple disabilities. These versions were tested for inter-rater reliability (consistency among raters), test-retest reliability (consistency over time), predictive validity (capability to predict related variables), concurrent validity (coherence with established assessments measuring similar factors such as the ICAP) and practical utility (ease of administration). Overall, the I-CAN achieved acceptable reliability and validity scores. Low test-retest reliability scores were, however, reported with some domains. This finding may reflect poor reliability or it may reflect the sensitivity of the I-CAN to identify real changes in the support needs of respondents[[359]](#footnote-359). The current version of the I-CAN, Version 4, is now being trialled on a sample of persons with intellectual disabilities, mental health difficulties, traumatic brain injury and spinal cord injury. The majority of the sample is in receipt of disability, mental health or rehabilitative services located in the eastern states of Australia. Initial statistical results from psychometric testing of Version 4 has been generally positive, however test-retest reliability scores have again been lower than expected[[360]](#footnote-360).

Version 4 (V4) has introduced an information and communication technologies (ICT) platform from which assessments can be completed directly onto an online server. The software includes dialogue boxes for both qualitative and quantitative data, and pop-up boxes that provide prompts and suggestions to assessors during the assessment interview. The software allows for the collection of a large dataset of profiles and provides standardised scoring and reporting facilities[[361]](#footnote-361). A web-based server database, however, as opposed to a more traditional offline database, generates concerns regarding questions of security and privacy, resulting in some government bodies declining to adopt the I-CAN due to policy guidelines regarding the use of internet technologies[[362]](#footnote-362).

The I-CAN V4 takes approximately one to two hours to complete and is administered through a semi-structured, self-assessment process where a trained facilitator guides the individual, accompanied by a family member and support staff, through the assessment[[363]](#footnote-363). As the I-CAN is a copyrighted tool, a brief overview of its content is presented based on material in the public domain. Both qualitative and quantitative data are gathered during the interview. Qualitative data are gathered on the individual’s demographics and additional personal information including support networks, and long-term goals[[364]](#footnote-364). Quantitative data are gathered on two core areas, Health & Well-Being and Activities & Participation.

Four domains are examined under Health and Well-Being;

* Physical Health,
* Mental & Emotional Health,
* Behaviours of Concern, and
* Health and Support Services.

Seven areas are examined under Activities & Participation:

* Applying knowledge, General tasks and demands
* Communication
* Self-care and Domestic life
* Mobility
* Interpersonal interactions and relationships
* Life Long Learning and
* Community, Social & Civic Living.

Each domain comprises a number of items for assessment. Under the Health and Well-Being domains, for example, items assess an array of health issues including, for example, the individual’s current status regarding ‘mobility’ and ‘medication management’[[365]](#footnote-365). Each item is rated with regard to the frequency with which support is required, ranging from support is never required to constant, that is ‘support is required a number of times or consistently throughout the day’. The items are also rated in terms of the level of support which is required, ranging from independent ‘person does not need any support’ to pervasive ‘person requires the direct support of two or more people due to this health need or to complete this activity’. The I-CAN V4 also gathers cost estimate data, that is, a costing based on the amount of hours of support a person requires. Costs are determined by apportioning salary rates (e.g. direct care, health professionals, allied health staff, etc.) and other costs (e.g. administrative costs, transport costs and ‘other’ costs) of the service an individual receives. A version of the I-CAN, the I-CAN Brief, is currently under development for application specifically in the area of resource allocation and individual funding[[366]](#footnote-366).

Once the data are gathered, a report is automatically generated which is given to the individual. The reporting facilities of the software include options to plot summary scores of an individual’s support need across the various domains and a facility to track changes in individuals’ progress by viewing illustrative graphs of assessments taken over different time periods[[367]](#footnote-367). The software also provides a quality control function whereby feedback is provided on the accuracy of the assessments, and in particular whether the assessment is erroneously reflecting individuals’ difficulties within a given area, rather than the level of support they require in that area[[368]](#footnote-368).

Implementation of the I-CAN to date is limited to Australia and New Zealand. To date, over 350 assessors have been trained and thousands of assessments have been undertaken. With regard to its usage as a resource allocation tool, a large study is currently underway in Victoria using the I-CAN brief with a sample of over 400 individuals, and interest has been expressed from the Tazmanian Disability Service for similar resource allocation work to be undertaken[[369]](#footnote-369),[[370]](#footnote-370).

In conclusion, the I-CAN has demonstrated robust psychometric properties, has been validated for use with persons with a wide range of disabilities, and has been developed with the potential for use at national level. It is the fourth criterion, that of having been used within the context of determining individual budgets, where the I-CAN has less implementation than the tools previously reviewed. The ongoing development and refinement of the I-CAN Brief, with a specific remit for use within a funding context, suggests that function will shortly be available within a growing suite of I-CAN assessments.

### 4.44 Comparative tables of In Control, SIS and I-CAN.

The tables presented in this section aim to provide easily accessible comparisons between the three support needs assessment tools. The first table presents a comparison of the key domains covered by each tool. The second table presents a comparison of the key psychometric properties of each scale. Finally, the third table presents a comparison of the how the three assessment tools compare against the four criteria used to determine their potential suitability for use as a key element of a resource allocation system for disability services in Ireland.

Comparisons by major domain across the three support measures should be interpreted with the following cautions. The In Control SAQ presented here is a template and as such differs from working tools being applied in the 150+ local councils throughout England. The SIS outline presented above includes all domains comprising the three sections of the scale. It is important to note, however, that some of these items are not typically included in the determination of a resource allocation, most particularly Section 2 which covers the areas of protection and advocacy. A similar caveat is required when reviewing the domains included in the I-CAN on the basis that the I-CAN Brief, not yet in the public domain, is the assessment tool that is currently under development for use in determining individual budgets. By definition the I-CAN Brief will contain a reduced number of items from the original I-CAN and as such some of the domains presented above are likely to be excluded in the determination of resource allocations.

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| Table 7: Comparison of support need assessment tools on key domains | | |
| In Control RAS5 SAQ | Supports Intensity Scale | I-CAN |
| Work and learning  Relationships and social inclusion  Choice and control  Support from friends and family  Family/Carer Role  Staying safe and taking risks  Meeting personal care needs  Eating and drinking  Practical aspects of daily living  Physical and mental wellbeing  Complex Needs and Risks | **Section 1:** Support Need Scale  Lifelong Learning Activities  Employment Activities  Social Activities  Community Living Activities  Health & Safety Activities  Home Living Activities  **Section 2:** Supplemental Protection and Advocacy Scale – typically this Section is not included in the determination of resource allocations.  **Section 3:** Exceptional Medical and Behavioral Support Needs – assesses level of support needed for medical and behavioural reasons. | Lifelong learning (includes employment)  Applying knowledge, general tasks and demands  Community, social and civic living  Interpersonal interactions & relationships  Self-care and domestic life  Mental and emotional health  Physical health  Behaviours of concern  Health and support services  Communication  Mobility |

An additional caution is required to acknowledge that the domains for all scales, as presented above, are not weighted according to their contribution to the resource allocation algorithms used to determine individual budgets. A comparison of the relevant weighting of domains would have required data from the resource allocation algorithms used by each scale. Such a comparison was not possible given that firstly, the RAS5 tool and algorithm differs across each local council and secondly, that the I-CAN algorithms are not in the public domain[[371]](#footnote-371). The comparison is therefore restricted to an observation of the domains presented above. Core domains covered across all assessment tools include employment and lifelong learning; protection, safety and behaviours of concern; personal and domestic needs; physical and mental health; social relationships; and community engagement. It is important to note that these domains are supplemented by a host of additional variables, such as demographics and type of service required, when determining a resource allocation[[372]](#footnote-372). Data from the initial studies examining the capacity of the SIS to predict costs, for example, found that 68% of costs could be predicted from an array of variables, of which 29% were directly predicted by the SIS[[373]](#footnote-373).

The second comparison between the three support needs assessment tools outlines the key psychometric properties associated with each tool. These comparisons do not include psychometric testing of the tools in other language versions. The In Control’s RAS5, as previously mentioned, has not undergone psychometric testing. This does not infer that the measure, and locally employed tools based on the measure, is invalid, but rather that the data have not been subject to psychometric testing. The comparison below is therefore restricted to presenting psychometric data on the SIS and I-CAN. In addition, the SIS psychometric data is available only for the scaled items in Section 1 which comprise the Support Needs Scale, and do not apply to the data gathered in Sections 2 and 3 on protection and medical supports respectively.

In interpreting the psychometric data presented below, it is important to note that the data refer to the potential of each assessment to validly measure support need. The data do not refer to the potential of the assessments to determine a resource allocation. Psychometric data are typically presented as correlation coefficients; a statistic ranging from -1.0 to +1.0 that defines the relationship between two variables. The closer a positive correlation is to 1.0 and the closer a negative correlation is to -0.1, the stronger the relationship between the two variables. Typically, high correlation coefficients are required to support the psychometric integrity of the tool in terms of reliability (the tool provides reliable data over time and across administrators) and validity (the tool measures what it claims to measure and not a related construct). An exception is concurrent validity where lower correlations between the measurements of two distinct constructs, such as support need and adaptive behaviour, indicate that they do not overlap. The table below presents key published psychometric data available for the SIS and I-CAN.

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| Table 8: Comparison of support need assessment tools on key psychometric variables | | |
| Psychometric test | SIS[[374]](#footnote-374) | I-CAN[[375]](#footnote-375) |
| Normed Sample (size of sample from which normed data was determined). | Normed on a sample of 1,306 people in 33 states in the US. | Normed on a sample of 1,012 people in 16 organisations in the eastern states of Australia. |
| Internal Reliability (degree of consistency between a person’s ratings on related items of the tool). | Exceeds 0.90 for all subscales of Section 1. | No comparable data. |
| Inter-rater Reliability (degree of consistency between administrators’ ratings of the same person). | Ranged from 0.35 to 0.79 in original testing but rose to 0.66 to 0.90 in subsequent testing[[376]](#footnote-376). | Ranged from 0.96 to 1.00; overall 0.99. |
| Test-retest Reliability (degree of consistency between a person’s ratings over two or more different time periods). | Ranges from 0.74 to 0.94 for all subscales of Section 1 over a three week interval. | Ranged 0.05 to 0.93 at one year and 0.01 to 0.94 at 2 years interval. |
| Content Validity (degree to which professionals agree that the full construct (support need) is measured by the tool). | Based on Q Sorting by 74 professionals in the field of developmental disabilities[[377]](#footnote-377). | No comparable data. |
| Concurrent/ Criterion-related Validity (degree of consistency between a person’s rating on the tool and similar measures or clinical judgement of professionals). | Ranged -0.23 to -0.68 against the ICAP, a tool which assesses adaptive behaviour.  Ranged from 0.46 to 0.66 against clinical judgement. | Ranged -0.39 to -0.62 against the ICAP, a tool which assesses adaptive behaviour. |
| Predictive Validity (degree to which a person’s rating on the tool can predict their performance on another measure). | No comparable data. | The predictive value of I-CAN to predict daytime support was R2=0.40 and 24 hour support was R2=0.27; that is 40% of variation in daytime support and 27% of is explained by I-CAN scores. |

With regard to the reliability of the two measures, the I-CAN has reported higher inter-rater reliability than the SIS. These psychometric findings suggest that the I-CAN is more likely than the SIS to produce consistent results across different administrators. In contrast, the SIS reported considerably higher test-retest reliability that the I-CAN indicating that it is more likely to produce consistent results over time. Commenting on the lower than expected test-retest findings of the I-CAN, the developers suggest that the findings do not necessarily infer any unreliability of the tool but may in fact reflect the sensitivity of the tool to respondents’ changes in lifestyle over the one to two year period of testing. Regarding the validity of the two scales, concurrent validity for both tools, that is a determination on whether the tools measure a distinct construct, has been assessed against the ICAP, a measure of adaptive behaviour. Both sets of analyses reported similar ranges of correlation coefficients indicating that the tools are measuring a construct independent of adaptive behaviour, that is, support need.

Finally, the third table below presents a comparison of the how the three assessment tools compare against the four criteria used to determine their potential suitability for use as a key element of a resource allocation system for disability services in Ireland. The four criteria comprised:

* whether they had been used previously within the context of determining individual budgets for people with disabilities;
* whether they had been developed with the potential for use at national level;
* whether they had robust psychometric properties;
* whether they were demonstrated to be appropriate for use with persons with a range of disabilities.

As the table reveals, each assessment measure performed well against the majority of the criteria, however, in all cases one criterion was not met. This does not mean that the measure does not have the capacity reach the criteria, but rather that the current evidence base would not allow for a final determination. The choice of any of these measures for application in Ireland may rest with the prioritisation of each criterion. Other things being equal, which is of greater importance, that the assessment tool be standard across all persons with disabilities, that it is psychometrically robust, or that it has been used elsewhere, successfully, as a resource allocation tool?

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| Table 9: Rating of support need assessment tools against review criteria | | | |
|  | In Control | SIS | I-CAN |
| Review criteria: |  |  |  |
| Used within the context of individual budgets | 🗸 | 🗸 | To be determined |
| Potential for use at national level | 🗸 | 🗸 | 🗸 |
| Robust psychometric properties | To be determined | 🗸 | 🗸 |
| Appropriate for use with people with range of disabilities | 🗸 | To be determined | 🗸 |

## 4.5 Allocating Resources on the Basis of Individual Support Needs: Key Summary Points

* The benefits of introducing a system-wide resource allocation model based on individual support need are multiple. From an equity perspective, people with most need receive the most support. From an enabling perspective, budget holders exercise control over their support and can change their provider secure in the knowledge that the ‘money follows the person’. From a transparency perspective, the format of standardised assessments of support need and the cost of service options should be clearly communicated and publicly available. From a cost perspective, savings of 10% and higher have been achieved where individual budgets have been introduced. Ultimately, any chosen resource allocation system should deliver quality outcomes not only for individuals but also for their families; the evidence suggests that individual funding models are associated with such quality outcomes.
* The Support Model represents a substantial paradigm shift within the disability field, moving to a focus on the individualised supports a person requires to achieve a particular lifestyle outcome, rather than a traditional focus on any perceived limitations a person may experience due to disability. The impact of the supports paradigm has substantially altered professional practices within the disabilities field, where assessment of support need has become a basis for individualised planning and resource allocation.
* The American Association on Intellectual and Developmental Disabilities (AAIDD) has developed a support model which outlines the various steps required to develop an individualised service based on support need; the steps include personal centred planning, assessing support need, developing an individual support plan, and finally, ongoing monitoring and evaluation of the plan to ensure personal outcomes are achieved.
* Individualised funding is defined as 'resources that are allocated based on needs which are identified through the planning process, to support the design and identification of supports that are flexible and responsive to individual need'.
* Individual funding models may be classified as retrospective or prospective. Retrospective models calculate the person's allocation during the person centred planning and support planning process. In contrast, prospective models determine the person's allocation prior to the development of their plan. Prospective models are favoured in the UK and US.
* The selection of appropriate support needs assessment tools is a key consideration in the development of a resource allocation system based on individual support need. Three measures were selected for review in this document: the In Control RAS 5, the AAIDD Supports Intensity Scale (SIS) and the Centre for Disability Studies, University of Sydney's Instrument for the Classification and Assessment of Support Need (I-CAN).
* Each measure was briefly reviewed and assessed against four criteria: whether it has been used within the context of determining individual budgets, whether it was developed for use at national as opposed to local level, whether it has demonstrated robust psychometrics, and whether it is appropriate for use across a range of persons with disabilities.
* In Control's system of self-directed support is credited with introducing the concept of personal budgets within the UK social care system. It is now in widespread use throughout local councils in England and is being introduced in a number of jurisdictions internationally.
* The In Control resource allocation system, RAS 5 (reflecting that it is now in its fifth iteration) is based on a self-assessment questionnaire (SAQ) of support need. Each SAQ item is allocated a 'point per price' cost which is determined locally by each council. The system is endorsed by the Association of Directors of Adult Social Services (ADASS) as a template RAS for their national Common Resource Allocation Framework.
* The RAS provides an indicative allocation which is finalised when the person's support plan is agreed. Self-directed support, as promoted by In Control, emphasises the personal outcomes individuals achieve rather than the determination of funding they receive.
* In Control's RAS 5 may be deemed to reach three of the four criteria set out above: it has been used extensively within the context of determining individual budgets, it has been used nationally, and it has been used across a wide range of persons with disabilities. It does not, however, have the weight of psychometric analyses that other tools have. This does not necessarily mean the data are not available, or sufficiently robust, for such analyses but does mitigate against a comprehensive evaluation of the tool.
* The Supports Intensity Scale (SIS) was developed over a five year period by the AAIDD for use by disability organisations working with persons with intellectual and developmental disabilities. The SIS comes with an extensive psychometric pedigree having been standardised on a large US sample. The SIS is used widely both in the US, currently in 14 states, and internationally, in 19 countries. It has been psychometrically tested in three foreign languages.
* In addition to its function as a support needs assessment, the SIS is widely used for resource allocation and service payment calculations. The Human Services Research Institute (HSRI) has considerable experience in implementing the SIS as a resource allocation system in a variety of jurisdictions. Administration of the scale requires extensive training by AAIDD to ensure the fidelity of the measure. Combined with financial data, the measure is commonly used to allocate individuals to funding levels, each with discrete funding ranges, based on individualised support need.
* The SIS may be deemed to reach three of the four criteria set out above: it has been used extensively within the context of determining individual budgets, it has been used nationally, and it has scientifically robust psychometric qualities. It has not, however, been extensively trialled with persons with a range of disabilities, but rather has been implemented for those with intellectual and developmental disabilities. The suitability of the scale items, and the normative data, may need to be reviewed to determine their suitability for use with persons with other disabilities, such as physical or sensory disability or those with mental health difficulties.
* The I-CAN (Instrument for the Classification and Assessment of Support Need) has been under development since the late 1990s by the Centre for Disability Studies, University of Sydney. Based on the theoretical frameworks of AAIDD and WHO's models of disability, the measure focuses on the interaction between individuals and their environments via an array of supports.
* Version 4 of the I-CAN utilises an ICT platform, essentially enabling assessments to be conducted online. The software allows for the collection of both qualitative and quantitative data and produces a wide range of reporting facilities. Financial data are captured by apportioning salary and related costs of an individual's service.
* I-CAN reaches three of the four review criteria; it has potential for use at national, as opposed to local level, it has been psychometrically tested, and it has application for persons with a range of disabilities. It has not, however, the level of implementation in the realm of determining individual budgets that has been observed for the tools previously reviewed.
* Attempts to compare the three support needs assessment tools, in terms of the key domains covered by each, proved challenging. The contribution of each domain within a resource allocation could not be determined for two of the tools and as such the comparison was limited to observation of the domains. All cover key areas such as employment, safety, personal care, physical and mental health, social relationships and community engagement.
* Attempts to compare the three support needs assessment tools on psychometric data were restricted to a comparison of the SIS and I-CAN, as In Control’s RAS5 does not have published psychometric data. Findings revealed that both measures were extensively tested, with the I-CAN reporting greater consistency in results across different administrators, and the SIS reporting greater consistency when administered over different time periods.
* A final comparison outlined the performance of each assessment tool on the four criteria set out above. The findings revealed that while each endorsed three of the four criteria, not one achieved success across all four. This does not mean that the measures do not have the capacity to reach the outstanding criteria, but rather that the current evidence base would not allow for a final determination. The choice of any of these measures for application in Ireland may rest with the prioritisation of each criterion. Other things being equal, which is of greater importance, that the assessment tool be standard across all persons with disabilities, that it is psychometrically robust, or that it has been used elsewhere, successfully, as a resource allocation tool?

# 5. Implementing a Resource Allocation Model based on Individual Support Needs in Ireland

## 5.1 Preparing for a new model of resource allocation in Ireland

The implementation of a resource allocation model based on individual support needs in Ireland would mark an important paradigm shift in the current configuration of disability support services. The move towards a more personalised model of support services, offering greater levels of choice and control for people with disabilities, is sought by a wide range of stakeholders including people with disabilities, their family and carers, disability providers, and by Government[[378]](#footnote-378),[[379]](#footnote-379),[[380]](#footnote-380). The recent reviews examining the delivery of disability services have certainly set expectations for radical change[[381]](#footnote-381).

The current funding of disability services is based on negotiations between disability provider organisations and the funding authority, whether HSE or Local Health Offices[[382]](#footnote-382). The allocation of funding from the Department of Health to HSE and Local Health Offices is under review and any proposed change in the resource allocation model within the disability sector would need to take cognisance of any such recommendations for substantial changes to the overall health funding allocation[[383]](#footnote-383),[[384]](#footnote-384).

Within the disability sector, funding negotiations currently involve a contract, without a tendering process, for the provision of disability services within specific geographical areas. These contracts, which are essentially of 'indefinite duration', involve block funding arrangements and are being replaced in international jurisdictions by more appropriate options. Change is already underway in Ireland. The recent introduction of Service Arrangements between disability organisations and their relevant funding body will provide a standard framework across disability providers from which funding can be negotiated. As a first step, these documents have the capacity to garner detailed information in a standard format from disability providers. This information would go some way towards addressing the dearth of funding information that is publicly available[[385]](#footnote-385). In due course, these arrangements should be populated by financial data based on individual support need similar to the data being developed by the Saint John of God services[[386]](#footnote-386). In this way, negotiations regarding funding would no longer based on 'slot placements' but rather on prospective budgets determined for each individual on the basis of support need.

Alternative funding options provide opportunities to open up the market for disability support services, thereby providing people with disabilities with real choice in selecting a service of their choosing, from a provider of their choosing[[387]](#footnote-387). Disability service providers in Ireland may need to be encouraged and supported to embrace such a change in their market. A system of registration and standards, such as that recently revised in the UK for the provision of adult social care, places a statutory requirement on all providers to register as a provider and to meet essential standards of quality and safety, irrespective of whether the support is provided in the person's own home or elsewhere[[388]](#footnote-388). Not only is the development of registration and standards of vital importance in ensuring that funding is linked to quantifiable standards[[389]](#footnote-389), but it is also of importance in providing a level playing pitch for those who wish to establish themselves in the market[[390]](#footnote-390). There is significant benefit to families in having choice of services of high quality in a number of locations, and ideally a range of alternative models of care.

Increased competition in the market would not only provide greater choice for those seeking services, but would also require providers to demonstrate greater transparency in the services they offer. The Comptroller and Auditor General has specifically identified a lack of accountability and transparency within the disability non-profit sector[[391]](#footnote-391). The unit cost of service provision within the disability sector, for example, is unknown. There is no 'average cost' of a placement other than estimates derived for the multi-annual investment programme where, for example, an 'average' residential place was estimated at €80,000. Even where 'average' costs could be determined, they would defeat the purposes of a resource allocation model based on individual support need. In order for provider organisations to negotiate with funding bodies using an individual support need mechanism, considerable work would be required in determining and apportioning costs across the service array. True transparency would be achieved when people with disabilities themselves are presented not only with the support services on offer from a given provider, but in addition, with the associated costs of each service element. Individuals may then compare the costs across providers in a truly informed manner.

The infrastructure required for a support needs model of individual funding may already exist. Part 2 of the Disability Act provides for the assessment of need of individuals who believe they have a disability[[392]](#footnote-392). As such, the personnel and technological framework for conducting assessments of need are already championed by legislation. The assessment process which currently focuses on younger children is, however, clinically intense in nature and is experiencing difficulties in reaching statutory timeframes[[393]](#footnote-393),[[394]](#footnote-394). The potential may exist to move from a system of highly clinical assessments, which may be more appropriately conducted within clinicians' ongoing intervention work, to a system of holistic and possibly self-assessment, within the context of a support model that assesses, plans and monitors individual support needs[[395]](#footnote-395). This latter model is intrinsically linked to the determination of prospective individual budgets based on individual support need[[396]](#footnote-396).

## 5.2 Late Mover Advantage

The implementation of a new resource allocation system for the provision of disability support services in Ireland would require considerable planning and effort. While there are undoubtedly cultural and historical issues specific to Ireland's structure of service delivery, valuable lessons can be learned from the experiences of those who have implemented similar initiatives in other jurisdictions[[397]](#footnote-397). Developments in the UK and US have been briefly documented in this report to provide an indication of how this challenge has been met elsewhere. While their experiences perhaps raise more questions than answers, a dialogue around these issues among all key stakeholders is a key starting point in the development of an Irish model of individual resource allocation. Some issues for consideration, based on experiences elsewhere include:

* the dovetailing of eligibility for disability services with assessment of support need and determination of a prospective individual budget - the Fair Access to Care criteria for eligibility in the UK, for example, is under consideration for a merger with assessments of support need.
* the development of a Common Assessment Framework across different stakeholders to reduce the need for duplicate assessment and administration.
* the development of local area agreements between local statutory, voluntary and private organisations.
* the use of commissioning of services to stimulate new entrants to the market and increase the availability of innovative support packages.
* consensus on the array of individual budget options to be delivered, whether personal budgets, individualised budgets with multiple funding streams, direct payments, individual service funds, or combinations of the above[[398]](#footnote-398).
* the selection of a retrospective or prospective budgetary model which, in turn, would raise further issues such as whether budgets would be capped to ensure the model remained budget neutral.
* the requirement for evidenced-based evaluative data on the implementation of a model and its impact across all stakeholders, including the quality of life impact on people with disabilities and, as appropriate, their families and carers, and the financial impact on disability service provision (the latter data having been described as 'patchy' in other jurisdictions[[399]](#footnote-399)).
* the promotion of an agenda for change in the delivery of disability services, whether through statutory and policy development, or more locally through the empowerment of leaders and advocates.
* the development of a service array that meets the current expectations of people with disabilities, and a monitoring of the likely migration from traditional in-house services to mainstream, personalised options.
* the impact on disability providers to facilitate the changing role of their organisations.
* the impact on direct care staff regarding possible employment outside of the HSE Employment Framework requirements of Section 38 funding.
* the development of new services such as brokerage to ensure people with disabilities receive independent guidance regarding their budget, and the development of support services for those who wish to become employers of their support staff.
* the development of information technology and finance systems to support the invoicing and payment of individual budgets.
* the emergence of regulatory bodies and standards to ensure funding is explicitly linked to the achievement of standards.
* the development of transition services to ensure there is no disruption in services to those moving from traditional to self-directed options.
* the emergence of guidelines on the services and supports that can, or cannot, be eligibly funded via individual budgets.
* the selection of an agreed methodology for the determination of individual budgets, (e.g. whether at individual or level basis, using custom made or standardised measures).
* the generation of financial data for the purposes of costing services and determining individual budgets (e.g. consideration of allowable and non-allowable costs for reimbursement).
* the establishment of demonstration projects as a first step in the development of self-directed services.

Ireland's late mover advantage in the implementation of individual budgets provides an opportunity to consider in depth the issues that have arisen in other jurisdictions. While some decisions, by their nature, would be made as the system unfolds[[400]](#footnote-400), many can be pre-empted by experiences elsewhere. A particularly well known framework of decisions for consideration in the implementation of individual budgets in the US, for example, hails from the National Association of State Directors of Developmental Disability Services (NASDDDS), an organisation that supports state agencies to deliver effective and efficient services to people with developmental disabilities[[401]](#footnote-401). NASDDDS acknowledge that while the setting of individual budgets may appear to be a simple matter of involving people receiving supports in discussions about their needs, services and costs, the manner in which states have set about implementing their resource allocation systems has been influenced by a myriad of local issues. NASDDDS has identified some of the key determinations that states must make in response to the basic questions of:

* 'who will be served?'
* 'what support services will be provided?'
* 'how much will be paid for support services'?

Each issue raises a series of questions which require considerable thought by those implementing the system. The issue of 'who will be served?', for example, prompts questions as to the eligibility criteria of the model:

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| Table 10.1: Who will be served? Individual Budget Decision Process in US States **(Moseley et al., 2005)[[402]](#footnote-402)** | |
| **Decision** | **Determination to make: Question to answer** |
| Who will be served?  Outcome: Identify recipient. | **1. Eligibility for services**   * what are the eligibility criteria? * how is eligibility determined? * is eligibility based on categorical or functional measures? * are services to be limited by eligibility category?   **2. Funding priorities**   * are services to eligible individuals restricted based on targeting criteria? |

In addressing 'what services are to be provided?', issues regarding the demand and availability of services must be considered:

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| Table 10.2: What services are to be provided? Individual Budget Decision Process in US States **(Moseley et al., 2005)[[403]](#footnote-403)** | |
| **Decision** | **Determination to make: Question to answer** |
| What services are to be provided?  Outcome: Set Support Plan | **1. Identification of needs**   * how are needs determined? * how are needs requiring support separated from those that do not?   **2. Identifying supports to be funded**   * what is the process for identifying the supports to be received? * is the process consistently applied? * does the process produce valid and reliable outcomes?   **3. Natural supports**   * which identified needs are best met by existing informal supports?   **4. Scope of services**   * what is the historical pattern of service funding and approval? * what is the scope of services that have traditionally been provided to people at similar levels or need? * what types of supports are required, restricted, or excluded?   **5. Preset limits and caps**   * what types of supports or services are limited by regulation or policy? |

Issues addressing 'how much will be paid for support services' are key to the determination of budgetary allocations:

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| Table 10.3: How much will be paid for support services? Individual Budget Decision Process in US States **(Moseley et al., 2005)[[404]](#footnote-404)** | |
| **Decision** | **Determination to make: Question to answer** |
| How much will be paid for services?  Outcome: Set budget amount | **1. Assigning costs to services**   * what is the evidence on which rates are based? * is the budget development methodology consistent throughout the jurisdiction? * are costs in line with historical trends? * are reimbursement rates preset or based on current costs?   **2. Preset limits and caps**   * are funds or services limited by caps or restrictions set through regulation or policy?   **3. Individual budget methodology**   * does it respond to changes in service need? * does it respond to individual choice? * does it have a process for appeals and dispute? * does it make sense to consumers and families? |

The NASDDDS decision process framework is helpful in outlining the scope of decisions that are required throughout the process of implementing a resource allocation system based on individual support need. These decisions require input from multiple stakeholders, ranging from people with disabilities themselves, to disability providers and onward to policy makers. A forum would be required whereby consultation and engagement on these issues can be deliberated. This might best be achieved within the context of a small number of demonstration projects conducted nationwide.

## 5.3 Implementing a Resource Allocation Model based on Individual Support Need in Ireland: Key Summary Points

* The proposed introduction of a resource allocation model based on individual support need in Ireland is timely. Recent reviews of the disability sector and the funding of health services, combined with the introduction of new negotiation agreements with disability providers have set an expectation of change.
* The market for disability support services is likely to change markedly with the introduction of self-direction and individual budgets. These changes must be linked with a system of registration and standards to ensure that funding is linked to standards. This is to ensure that only those services which reach an acceptable standard can be funded, and to avoid competition resulting in a ‘race to the bottom’. A system of registration linked to standards can also ensure that new entrants may join the market.
* Greater financial transparency would be required of disability providers to ensure that people with disabilities, who would now be offered the opportunity to manage the budget for their supports, can make an informed choice when selecting disability support services.
* The robust resource allocation systems reviewed in this report deal in the main with social care services for adults. While both In Control and the SIS are currently developing tools for application with children, the effectiveness of these tools and the application to health services such as therapeutic services and other medical supports requires further exploration. In addition, the alignment of such tools with the statutory needs assessment process under the Disability Act requires in-depth investigation.
* Ireland has 'late mover advantage' and can learn from the experiences in other jurisdictions where resource allocation models based on support need have been implemented. While there are undoubtedly cultural differences, the experiences of others can assist in raising issues for consideration, and possibly pre-empting mistakes made elsewhere.

# Appendix A: In Control - Example of Self Assessment Questionnaire (with kind permission of John Waters, In Control; available at www.incontrol.co.uk)

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| **Meeting personal care needs**  This part is about looking after yourself – things like washing, dressing and going to the toilet |  | Points | Outcome |
| A) I need a lot of support with all my personal care (washing, dressing, going to the toilet). I need help during the day and night. I need someone around me day and night to make sure my personal care needs are met. |  | **15** | To be clean and dressed |
| B) I often need help with personal care during the day. I need someone around most of the time to make sure my personal care needs are met. |  | **7** |
| C) I need support now and then with personal care. I’m OK for **short** periods on my own– I need some one around some of the time. |  | **5** |
| D) I occasionally need help with personal care. I can stay on my own for quite **long** periods. |  | **3** |
| E) I very rarely need support to look after myself. I’m OK on my own in most places – for days at a time. I do not require help to meet my personal care needs |  | **0** |

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| **Eating and Drinking (Nutritional needs)**  This part is about looking after yourself, and staying fit and well nourished – eating and drinking properly. |  | Points | Outcomes |
| A) I need lots of help to eat and drink, I need to be fed and given drinks. |  | **15** | To be well nourished and remain hydrated |
| B) I need help and encouragement to eat and drink, enough to stay well. |  | **7** |
| C) I need all my meals to be provided or prepared for me |  | **3** |
| D) I do not need help in this area |  | **0** |

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| **Practical aspects of daily living**  This Part is about day to day life; things like, shopping, cleaning, cooking, and doing the laundry. | | Points | Outcomes |
| A) I need help with most things around the home: I need lots of help with my shopping, laundry, housework, managing finances, paying bills, and general home maintenance. |  | **6** | For my home and household affairs to be well managed and maintained. |
| B) I need help with some things around the home : I need some help with shopping, laundry, housework, managing finances, paying bills, and general home maintenance |  | **4** |
| C) I need only occasional help with some things around the home: I occasionally need some help with shopping, laundry, housework, managing finances, paying bills, and general home maintenance |  | **2** |
| D) I don’t need help with very much around the home |  | **0** |

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| **Physical and Mental Well being**  This part refers to support you may need to manage your health, either a physical condition (e.g. diabetes, heart or respiratory failure, stroke, epilepsy etc) or a mental condition (eg depression, anxiety state, bereavement, dementia etc). | | | |
|  | | Points | Outcomes |
| A) I need a lot of help from others to ensure I stay well and there is real concern about my complex health needs. |  | **6** | For physical and mental wellbeing to be maintained |
| B) I need some help from others to make sure I stay well and there is some concern about my complex health needs |  | **4** |
| C) I need a little help from others to make sure I stay well. |  | **2** |
| D) I am well and no-one has raised concerns about my health or welfare. |  | **0** |

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| **Relationships & Social Inclusion**  This part is about doing things in your community, like using local shops, the library, going to a luncheon club or the community centre, church or other place of worship, visiting neighbours, or being involved in local organisations. It also looks at being with friends.  Your community might be the people and places that are in your local area or you may think of your community as the people and places that are important to you because of who your religion or ethnic origin. | | | |
|  |  | Points | Outcomes |
| A) I need a lot of regular and ongoing support to do things in my local community. |  | **6** | To be able to access my community |
| B) I need regular and ongoing support to do things in my local community. |  | **4** |
| C) I need some Occasional support to do things in my community. |  | **2** |
| D) I don’t need any support to do things in my community. |  | **0** |

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| **Choice and Control**  This part is about who decides important things in your life – things like where you live, who supports you, who decides how your money is spent. You may have less control over your life having become forgetful or confused, or you may be depressed. | | Points | Outcomes |
| A) Other people make most decisions about my life. I need a lot of support to make more decisions, and take more control. |  | **5** | To have choice and control over decisions effecting my life |
| B) I decide most day-to-day things. But I don’t have much say in important decisions about my life. I need some support to make decisions. |  | **3** |
| C) I make all the decisions. I need occasional advise and support to make them. |  | **1** |
| D) I do not need help to make choices or decisions, I make all the decisions. I just need a bit of advice. I have full capacity and understanding. |  | **0** |

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| **Staying safe taking risks**  This part is about keeping safe, you may face risks when you are going out on a bus, or using a cooker, or going up and down stairs. Staying safe is about different things for different people.  Some situations where there are quite high risk can be managed by using technology, if you require support to manage risks you should, find out about what tele-care is available in your area. | | | |
|  |  | Points | Outcomes |
| A) I need help to stay safe a lot of the time, and I need a lot of support to stay safe. People worry a lot about my safety. There are no tele-care options that would help reduce the risks I face. |  | **20** | To be safe and benefit from responsible risk taking |
| B) I need help much of the time to stay safe. People worry about my safety. There are no tele-care options that would help reduce the risks I face. |  | **12** |
| C) I need help some of the time to stay safe . People worry a bit about my safety. (There are real risks but these can be managed well with tele-care) |  | **7** |
| D) Sometimes I need a little help to stay safe. I’m happy and no-one says they’re too worried. |  | **3** |
| E) I don’t need help to stay safe. I’m happy and no-one says they’re worried. |  | **0** |

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| **Work and learning**  This part is about taking part in work and learning. |  | Points | Outcomes |
| A) I need constant and ongoing support to take part in work or training, and be usefully occupied. |  | **25** | To take part in work and learning. |
| B) I need help much of the time to take part in work or training, and be usefully occupied. |  | **20** |
| C) I need help some of the time to take part in work or training, and be usefully occupied. |  | **12** |
| D) Occasionally I need a little help to take part in work or training, and be usefully occupied. |  | **7** |
| E) I don’t need any support to take part in work and learning or I am retired from work. |  | **0** |

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| **Support from friends family and community**  This part is about the support available to you from friends and family. The amount of support you have will effect your personal budget allocation. | | **Points** |
| 1 | I am able to get nearly all the help I need from my family and friends | **.4** |
| 2 | I am able to get most of the help I need from family and friends | **.6** |
| 3 | I am able to get only some of the help I need from family and friends | **.8** |
| 4 | I can get little or no help at all from family or friends | **1** |

# Appendix B: A comparison, from 2006, of three support needs assessment instruments conducted by the HSRI to advise the Colorado Division for Developmental Disabilities.

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| **Inventory for Client and Agency Planning (ICAP)** | |
| **Scope** | Developed in 1980s assesses (i) adaptive and (ii) maladaptive behaviours (iii) demographics (iv) service utilisation. Not originally developed for rate determination. Adults and children 3+ |
| **Detail** | 185 items in total. Scores from (i) and (ii) are used to calculate a Service Level Index score which reflects the level of supervision or training an individual might need. Scores are based 70/30 on adaptive maladaptive behaviours. Scores are grouped into nine levels with higher scores reflecting less supported needed. |
| **Psychometrics** | Has 'acceptable psychometric properties'. Normed on a sample of n=1,764 with some weakness noted for norming of small children and construct validity. |
| **Strengths/ weaknesses** | Strengths - psychometrics are sound, robust, for use with children and adults, compact, easily scored, used widely. Weaknesses - health status not included in index, doesn't apply well to service plans, doesn't assess support needs per se, omissions of employment, carers, focuses on deficits, scoring bias, repetitive |
| **Administration** | 30 minutes by person who knows the individual well (for at least three months and sees the person daily). May require other informants. |
| **Training** | Typically administered by service providers - or may be sub-contracted to third party who consult with key informants. Those administering the tool must be trained. Training manual exists and is well designed - takes approx 1 day. Evidence of administration bias depending on who completes it |
| **Implementation Costs** | Purchased from Riverside Press. Manual & 25 booklets costs $167.50. Additional booklets costs $65.00 for 25. Software package is $285.00. Cost for full implementation in Colorado $22k and $4 for ongoing completion every 2-3 years |
| **Training Costs** | One day session at a central site for a number of assessors $3-5k. Could use a train the trainer approach. |
| **IT considerations** | ICAP 'Compuscore' package. Some technical difficulties encountered. |
| **Ongoing technical support** | Defined as unclear. |
| **How is it used in states?** | 17 states use it in one fashion or another - some just to assess eligibility for services. Examples of its use for service payment rates: Tennessee - (Service Level Index scores classified to 6 levels) Texas, Louisiana, Illinois, Wyoming, South Dakota, Utah, Nebraska,. |

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| **Supports Intensity Scale (SIS­)** | |
| **Scope** | Established in 2004 by AAIDD. Adult version available. Child version under development. Directly feeds into and supports the development of person-centered plans. |
| **Detail** | Subscales of Home Living, Community Living, Lifelong learning, Employment, Health & Safety, Social. Need for support is measured in terms of frequency, amount and type. Total scores, subscale scores, broad medical and behavioural supports. SIS Plus for additional demographics |
| **Psychometrics** | Normed on a sample of n=1,306. Extensive psychometric testing. |
| **Strengths/ weaknesses** | Strengths - Focus on support needs, contributes to effective individual service plan development, directly assesses support needs, includes focus on employment, acceptable psychometrics, multiple informants. Weaknesses - administered by skilled interviewers, baseline needs supplement, some psychometric issues, child version soon. |
| **Administration** | By multiple informants so takes longer than other instruments. 45-60 minutes per informant. |
| **Training** | Requires training. Administration is usually by case managers. |
| **Implementation Costs** | Must be purchased from AAIDD ($1.50 per booklet). Costs to implement completely to Colorado is $11k and approx $3k per annum. Scoring software is $325. Online version allows data to be uploaded to local server - this is more expensive option. |
| **Training Costs** | Training through AAIDD at $2k per day plus expenses. This could equate to $12k for a pilot. Variable factors are numbers of persons to be trained. Train the trainer is an option. Administration costs are about $100-120 per consumer (twice ICAP). |
| **IT considerations** | Some states have integrated SIS software into their own data systems to avoid difficulties. Other options include SIS Online or a CD ROM version to develop a state database. |
| **Ongoing technical support** | Provided by AAIDD - extensive. |
| **How is it used in states?** | By 2006, the tool was only available for two years but was used extensively both as (i) a baseline assessment tool and (ii) as a funding related tool. Georgia and Washington are the farthest along in using SIS for funding. |

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| **Comprehensive Services Assessment Tool (C-SAT) / Colorado Assessment Tool (CAT)** | |
| **Scope** | C-SAT developed in 2001 and aimed to identify support needs that drive costs. It is 'not a rate determination tool per se'. CAT is a modified version to increase coverage of waiver recipients. |
| **Detail** | C-SAT is 3 pages with 5 areas reviewed over previous 12 months. Scoring results in the assignment of individuals to one of five clusters. CAT is 3 pages with 4 domains. Scoring algorithm hasn't been finalised. CAT C-SAT and MONO all based on cost drivers. |
| **Psychometrics** | C-SAT some psychometrics which have found some difficulties with the tool. CAT - not possible to establish yet |
| **Strengths/ weaknesses** | Strengths - Compact, face validity, objective. Weaknesses - geared towards adults, C-SAT scoring algorithm is unsatisfactory, administration doesn't involve consumer, some items excluded that bear on informal supports. |
| **Administration** | 40 minutes. By primary service provider and case manager. |
| **Training** | Doesn't require clinical experience but does require training. Training takes 3 hours and is repeated annually. Instruction manual is user friendly. |
| **Implementation Costs** | Understand that as tool is produced with state funds it should be free. |
| **Training Costs** | Should be significantly less than with 'national' tools. |
| **IT considerations** | Uses MSAccess. |
| **Ongoing technical support** | Not available. |
| **How is it used in states?** | C-SAT used by 4 CCBs in relation to funding. CAT no experience yet. |

1. National Disability Authority (2010), Progressing the Disability Agenda: Strategic Plan 2010-2012. NDA, Dublin. [↑](#footnote-ref-1)
2. NDA (2010) submission to the Value for Money Review. Available at http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/F1D157570980DF218025778100507AD0/$File/NDA\_policy\_advice\_paper\_July2010\_VFM\_review\_disability\_services.pdf Accessed 14th February 2011 [↑](#footnote-ref-2)
3. Central Statistics Office (2008) National Disability Survey 2006, First Results. Available at http://www.cso.ie/releasespublications/documents/other\_releases/nationaldisability/National%20Disability%20Survey%202006%20First%20Results%20full%20report.pdf, Accessed 14th February 2011. Table 1.6 reports that 67% of those who declared a disability on both Census 2006 and the National Disability Survey (n=325,800) stated that they experienced 'a lot of difficulty' or 'cannot do' everyday tasks. [↑](#footnote-ref-3)
4. Approximately 26,000 individuals voluntarily registered with the National Intellectual Disability Database and 30,000 individuals aged 65 and younger voluntarily registered with the National Physical and Sensory Disability Database. [↑](#footnote-ref-4)
5. Specialist disability services as defined by the Value for Money and Policy Review of disability services. http://www.dohc.ie/consultations/closed/effectiveness\_disability\_services/consultation\_doc.pdf?direct=1, Accessed 14th February 2011. [↑](#footnote-ref-5)
6. National Disability Authority (2010). Advice paper to the Value for Money and Policy Review of Disability Services Programme. Dublin, National Disability Authority. [↑](#footnote-ref-6)
7. Disability Federation of Ireland (2010). Position paper on the Value for Money and Policy Review of the Disability Services Programme. [↑](#footnote-ref-7)
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22. formerly termed 'Section 26'. [↑](#footnote-ref-22)
23. http://www.irishstatutebook.ie/2004/en/act/pub/0042/sec0038.html, Accessed 14th February 2011. [↑](#footnote-ref-23)
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34. http://www.oireachtas.ie/documents/committees30thdail/pac/additional\_documents/20101014-3.1.pdf, Accessed 15th February 2011. [↑](#footnote-ref-34)
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36. The generic resource allocation model template - albeit not currently in use - provides for the collection of 'service outcome' data. These data pertain to 'anticipated outcomes that service will deliver so that they can be monitored and evaluated. The template notes 'this is on the basis that there needs to be an increasing emphasis on results, i.e. outcomes'. Proposed outcomes include the number of individuals taking up supported employment and facilitating individuals in receipt of services to reach their potential. [↑](#footnote-ref-36)
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53. Ibid. [↑](#footnote-ref-53)
54. Ibid., Table 23 page 67. [↑](#footnote-ref-54)
55. Department of Health and Children (2010). Report of the Expert Group on Resource Allocation and Financing in the Health Sector. Department of Health and Children, Dublin. [↑](#footnote-ref-55)
56. The Report proposed that the current allocation of health funding may in fact deter individuals from using health services in a manner promoted by health policy. Individuals in need of health services, for example, may be dis-incentivised to receive treatment in primary and community care settings due to the lower cost of presenting for comparable services provided at lower cost within the emergency departments of acute hospital settings. Noting the need for reform of the current resource allocation system in Ireland, and following a review of resource allocation models in eight international jurisdictions, the report proposes a framework for resource allocation for integrated health-care delivery in Ireland. The framework proposes a graduated level of primary care subsidisation comprising four entitlement categories reflecting different income and health circumstances. [↑](#footnote-ref-56)
57. The Expert Group guiding principles state that a resource allocation system should be transparent and based on population need; should be systematically implemented at local level to avoid unintended disparities across groups or areas; should support the delivery of services in the most appropriate setting; should promote the integration of services across primary, hospital and community/continuing care sectors; should ensure that financial incentives promote good health and well-being; should be as effective and equitable as possible; and should ensure that the expenditure is sustainable and provides value for money. [↑](#footnote-ref-57)
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59. McDaid D, Wiley M, Maresso A & Mossialos E. (2009). Ireland: Health system review. Health Systems in Transition,11(4) 1 – 268. [↑](#footnote-ref-59)
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61. Department of Health and Children (2010). Report of the Expert Group on Resource Allocation and Financing in the Health Sector. Department of Health and Children, Dublin. [↑](#footnote-ref-61)
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66. Ruane, F., (2010). Towards a better and sustainable health care system - resource allocation and financing issues for Ireland. Economic and Social Research Institute, Working Paper No. 358. [↑](#footnote-ref-66)
67. http://www.oireachtas.ie/documents/bills28/acts/2005/a1405.pdf, Accessed 15th February 2011. [↑](#footnote-ref-67)
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