Resource allocation models for disability services: assessment of four systems



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# Summary

This paper presents the National Disability Authority’s assessment of the four resource allocation systems for disability services which it studied, namely FACE, InterRAI, In Control’s Resource Allocation System 5 (RAS 5), and the Supports Intensity Scale (SIS).

The National Disability Authority would recommend choosing an existing validated resource allocation system, rather than building an independent or a hybrid system.

The National Disability Authority also recommends taking an existing costing system associated with the chosen tool, rather than creating a new formula to link assessments and budgets. The cost formula should be adjusted to reflect Irish wage levels. The link between the nature of impairment and functionality, and support hours required, is likely to be similar, whatever the jurisdiction where the cost relationship was derived. That costing system should be fine-tuned over time as data on Irish service users becomes available.

While all four tools tested are in broad terms similarly effective at measuring need, FACE and interRai are the tools which offer off-the-shelf systems to predict disability support costs. FACE scores highest in terms of accuracy of its costing method. FACE would also be capable of being implemented earlier than interRai, as initial resource testing of the intellectual disability interRai tool was only completed in the summer of 2014, and an official cross-disability interRai instrument has yet to be developed. Therefore for accuracy, practical and timing reasons, the preferred resource allocation system for disability services is FACE. The second choice would be interRAI.

The four assessment tools are primarily designed to predict the amount of personal support hours required, but not to gauge specific clinical needs, assistive technology, nor to predict the need for background supports such as peer advice and information. None of the four assessment tools examined constitute a full clinical assessment. While areas of functional difficulty highlighted may point to the need for some therapy support, none of the assessment tools are designed to predict the amount of such support required. Neither are any of the tools designed to predict what assistive technology any individual would require or what that might cost. Therefore, if a resource allocation system is to be used as a basis for budgeting for disability services certain elements of disability services, namely therapies, assistive technology, and community peer-support groups, should be outside the resource allocation framework and funded separately.

The National Disability Authority also examined how the different assessment systems used for resource allocation might be helpful for other planning or management purposes such as aggregate service planning or person-centred planning. Overall, the value of having a single national assessment system where individuals can be compared across regions, services or service units, or over time, was considered to be the main advantage, irrespective of which of the four assessment systems would be chosen. Because each of the tools results in similar support needs profiles, it would not make much difference which one would be used for aggregate service planning. The value of having a common system of assessment enabling comparisons to be drawn between services, and data from different services to be readily combined, is probably more important than the choice of specific system.

There is potential for the data collected through the assessment process to contribute to other management and planning processes, such as measurement of outcomes or quality assurance. The simplest and shortest of the four tools, RAS 5, was considered to add the least value. The other three assessment schedules offered richer potential sources of management and planning information. Of these three, interRai collects the most detailed set of information.

While person-centred planning is a wider process than support needs assessment, the Supports Intensity Scale was the best suited system to support person-centred planning and local service plans.

Interoperability between older persons’ services and disability services would be maximised by choosing the disability instrument from the interRai family, as this is the single assessment tool chosen for older persons’ services. However, in practice, interoperability might not be a significant issue. Individuals who transfer to older persons’ services may do so because of a change in circumstances, which would in any event require a fresh assessment.[[1]](#footnote-1) Baseline data from a previous assessment using other tools would be available to the new assessor, even if not supplied in readily interoperable machine-readable form, nor with identical terms used.

## Procurement

FACE is a commercial system, and if it is the option chosen by the Department of Health/HSE, procurement negotiations would be required in order to ensure value for money for the public purse. While it can be operated via a simple Excel spreadsheet, for optimum user-friendliness and robustness, and to facilitate the generation of special reports to maximise the value of the information collected, a specialised software solution would be best. This could either be the FACE proprietary software or a bespoke solution. A procurement process would ensure best value for the associated software.

InterRai is produced by academics, and is available for a nominal fee, but requires special software to run it. This can be procured via a range of interRai-competent software companies, or via building a bespoke solution (the approach taken for the InterRai eldercare product).

While final costs would depend on a procurement process, preliminary assessment suggests that if a separate software system would need to be built for an interRai disability application, this might be broadly the same order of cost as buying the full FACE suite of applications. A separate paper, with commercially sensitive information looks at possible costs of purchase of alternative systems.

Resource allocation models for disability services: assessment of four systems

# Introduction

The National Disability Authority (NDA) has undertaken a programme of research to inform the choice of an assessment tool and resource allocation system for Ireland in order to support a system of funding that reflects needs, a move to individualised funding, and the introduction of personal budgets. This paper sets out a detailed evaluation and comparison of four different systems

* FACE (Functional Assessment of Care Environments)
* InterRAI
* Support Intensity Scale® (SIS)
* In Control’s Resource Allocation System 5 (RAS 5)

## Features of resource allocation systems

The resource allocation systems for disability services reviewed here consist of

* a standard questionnaire that documents the individual’s capabilities and support needs across a number of domains
* a scoring system that can rank support needs from high to low
* a system for translating scores on the support needs assessment into a budget requirement

Each of the four tools captures information relevant to an individual’s support needs, covering domains such as personal care, health and nutrition, self-care, mobility, emotional well-being, behaviour support, decision-making, managing one’s home and finances, and participation in education, work or community life. (See appendix 1 for a listing of the domains each tool covers.)

None of the four tools studied is a clinical assessment, although some record that there are additional clinical needs. Rather each tool records information on individuals’ capacities and support needs in a standardised way.

## NDA research on resource allocation systems

The National Disability Authority programme of research on resource allocation systems included a review of literature, meetings with key international experts, study visits to sites in the UK, and two successive field trials of questionnaires associated with the different systems. The field trials collected feedback from service users, families and key workers, and the interviewers who administered the questionnaires. This programme of research has been supported by an Advisory Committee which included representatives from the Department of Health, the HSE, Inclusion Ireland, Disability Federation of Ireland, and the service provider umbrella groups the Not for Profit Business Association and the National Federation of Voluntary Bodies.

### Discussion paper and literature review

The first stage was a discussion paper drawing on a review of literature on resource allocation.[[2]](#footnote-2) This focused in particular on three systems – In Control’s RAS 5, the Supports Intensity Scale (SIS), and I-CAN. In Control’s RAS 5, or local variants, is widely used in the UK for allocating personal budgets for social care across different care groups (elderly, people with disabilities, people with mental health difficulties). The Supports Intensity Scale was developed by the American Association of Intellectual Disability Directors to assess the support needs of people with intellectual disabilities, and its scoring system has been standardised on that population, but it has also been used, notably in the Netherlands, for people with physical disabilities. I-CAN is an Australian system, which at that stage was not in widespread use.

### Field trial 1 – RAS 5 and SIS

The second stage was a field trial of assessments using RAS 5 and SIS, in which both questionnaires were administered by trained interviewers to 112 people across a range of disabilities, residential circumstances, and regions. The evaluation showed strong similarities between the rankings achieved using the simpler instrument (RAS 5) and the more in-depth instrument (SIS).[[3]](#footnote-3)

### Field trial 2 – FACE and interRAI[[4]](#footnote-4)

The third stage was a second field trial, with forty participants from the first field trail, of assessments using FACE and interRAI. FACE (Functional Analysis of Care Environments) is in use in the UK by a number of local authorities as an assessment system for resource allocation. In Ireland, some mental health services also use FACE. InterRAI has been chosen as the single assessment tool in Ireland for older person’s services. It is used in the US and other jurisdictions.

The assessment looked at the results across the field trials of the four instruments. Statistical analysis showed strong correlations between the four assessment tools. This is not surprising, given that each collects similar core information around key drivers of care and support needs. Some differences between the tools were also identified.

### Conclusions from field trials

In general, the conclusion of both field trials was that each instrument produced a ranking of support needs that was not very different from that produced by the other instruments. In general, each tool was considered acceptable by service users, keyworkers, family members and interviewers. The RAS 5 interviews took less time than the others, as it was a shorter instrument, however this short instrument produced broadly similar rankings of support needs as the other instruments which collected more detailed information. The overall conclusions of this phase of the research were

* any of the reviewed tools could provide an acceptable system of identifying the level of support needs
* the choice as to which tool to opt for would depend on other factors, such as how well they served to predict costs, and how useful the information collected would be in informing other processes such as forecasting service requirements or person-centred planning

## Organisation of paper

The primary role envisaged for any new assessment system is to inform the allocation of resources. Conducting individual assessments of support needs for up to 70,000 service users (around 50,000 of them adults)[[5]](#footnote-5) is a labour-intensive exercise therefore this paper also examines the potential to use the standardised information collected for other aspects of the management and delivery of disability services.

This paper is divided in three parts.

**Part 1** examines the strengths and weaknesses of the four systems from the perspective of resource allocation.

**Part 2** examines the strengths and weaknesses of the four assessment tools across a range of other possible uses, and addresses specific questions raised the Department of Health asked the National Disability Authority to examine.

**Part 3** uses a scoring system to calculate how the different tools would score against each other. Each tool was first of all scored on individual success criteria. Then two different weighting systems were used. The first was a system devised by the National Disability Authority, which assigned the greatest weighting to the accuracy of estimates of resources required by different individuals. The four tools were also scored using the weighting system adopted by the HSE group which explored a single assessment tool for older people.[[6]](#footnote-6) In each case, the conclusion was the same. FACE is the preferred tool, followed by interRAI, then by SIS and RAS 5.

Part 1 – Resource allocation

The primary purpose of a resource allocation system is to provide robust estimates of the costs of disability support services to people. How well the different systems perform in allocating resources is therefore the most important consideration in selecting a preferred system.

# 1.1 What cost drivers are captured

The four tools capture key drivers of social care and support needs, with a focus on activities of daily living, and support to participate in normal life. No tool captures clinical needs, though some can predict where a clinical assessment may be indicated. The Supports Intensity Scale does not cover the availability of family or community support, which is a major influence on service requirements.

The findings of the NDA’s analysis of the results of the field trials of the four assessment tools showed that they all produced broadly equivalent results in estimating support needs, whether a simple assessment with 9 items (RAS 5), or assessments which recorded a greater level of detail (FACE, SIS or interRai).[[7]](#footnote-7) A small number of core areas of support need are the main drivers of cost.

## Hours of care support

A resource allocation tool should be able to predict sufficient resources to cover the hours of care support a person needs and the associated overheads. In different jurisdictions, the tools will predict different cost figures, but it is possible, using local pay and conditions, to derive an estimate of hours of care support embedded in the costing formula.

### Support hours requirements largely independent of jurisdiction

If we assume that the hours of care support an individual will require, given the level of sustainable family and community support available to them, is independent of the jurisdiction in which they live, then cost formulas derived for other jurisdictions can be used as a good starting point for calculating relevant costs in Ireland. For example, someone who needs daily support to get out of bed and get dressed, and who cannot eat independently, will presumably need similar levels of support input, irrespective of which country they live in. An exception would be where there are significant differences between jurisdictions in how supports might be delivered or in what support needs would be covered. The cost figures from another jurisdiction can be converted into the underlying care support hours, and this in turn can be used to work out the equivalent costs for Ireland using Irish pay scales.

The interRAI eldercare instrument has been used in several countries with almost identical results in terms of cost profiles, illustrating this point that care support needs are related to the individual’s level of capacity and dependency, and are largely independent of jurisdiction.

Both FACE and interRAI assessments have procedures which can generate estimates of costs based respectively on equivalent UK and US costs or hours of care. These could be used to generate equivalent costs in an Irish context.

## Progressive needs

Some people have progressive conditions wherethe degree of intensity of support required will increase over time. Individuals in these circumstances will need more frequent reassessments of their needs than those whose support needs are stable, if resources are to accurately match their changing needs.

In looking at aggregate needs, a snapshot at a particular point in time will capture a spectrum of support needs for people with progressive conditions, from early to late stage. This can offer a reasonable guide for macro-level planning and resource allocation across large groups of people, for example at the level of Community Healthcare Organisations, but would be unreliable in terms of smaller units such as an individual service, where a greater degree of variation would be expected. A resource allocation system used to assign budgets as between providers on the basis of case mix might therefore hold some money in reserve to allow for variations in support needs related to progressive conditions.

## Episodic needs

People with some conditions have episodic needs for intensive support, and other periods where support needs are low. Again these are circumstances where more frequent reassessments may be required by individuals as their circumstances change.

For aggregate planning purposes, a snapshot at a point in time will capture people at different states of episodic conditions, and can help forecast aggregate need over large groups. As in the case of those with progressive conditions, a snapshot can be an unreliable guide as to the spectrum of need where the numbers are small.

So, single point-of-time assessments can be used for aggregate national and regional planning. Larger service providers may be able to smooth their deployment of the allocated resources to deal with episodic and progressive support requirements. There may be greater variability where the provider is a small one. Data pooling, for example within a region or Community Healthcare Organisation, together with a shared reserve pot could help smooth the matching of resources to the needs profile in individual services, to take account of the variability of episodic and progressive support needs. However more frequent individual assessment would be required to inform the resources to be allocated to individuals.

## None of the systems assess clinical nor assistive technology needs

At the outset, it is important to be clear about what resources these tools can predict. As mentioned above, none of the four tools studied constitutes a clinical assessment. The tools record information on people’s capacities and personal support needs around activities of daily living and inclusion in society.

None of the tools are therefore able to predict the type and quantity of therapy supports an individual may require (e.g. speech and language therapy, physiotherapy or occupational therapy), nor the need for specific assistive technologies. Some of the tools have developed formulas to predict that such inputs may be required, and can suggest referral for clinical assessment. For example, InterRai has developed a series of Clinical Assessment Protocols that are triggered by answers to specific questions. However, the tools cannot predict the amount of such inputs nor the likely cost. That would require individual clinical assessments. None of the tools can predict how many sessions of speech therapy an individual may need, or whether they would require an electric or a manual wheelchair. So while the profile of the individual might record that the person had speech or swallowing difficulties, or that the person could not walk, the tools are not able to predict a cost around therapy or assistive technology inputs.

## Peer support, information, advocacy and community services

A number of organisations funded or co-funded by the HSE provide peer support, information, advocacy and linkages to community services for people with specific conditions. Such organisations may provide transition training and support to individuals who are newly diagnosed with a particular condition, advice and information on living with a particular condition, advice on assistive technologies, put people in touch with others with the same condition, run social events or support groups in local communities, provide advice and information to doctors and other professionals. People with stable and low-dependency disability may need short-term help to manage transitions such as a change of job requiring a change in assistive technology and familiarisation with a new location. None of the resource allocation models are well geared to predict either individual or collective demand for these type of services. [[8]](#footnote-8)

## Exclusions from resource allocation system

The resource allocation systems studied are designed to model requirements for personal support services, such as day services, residential supports, and personal assistance. They are not geared to assess the level of resources required for multi-disciplinary therapy, for assistive technology, nor for information advice or training on living with a particular condition, So if a resource allocation system is introduced, certain elements of the disability services budget would fall outside it and would remain to be funded separately.

In other words, if €200m is spent on therapy supports, assistive technologies, and community peer-support advice and information, out of a total €1.5bn budget for disability services, a resource allocation system could only inform the distribution of the remaining €1.3m.[[9]](#footnote-9)

## Access to family and other unpaid support

One of the most significant drivers of an individual’s support costs is to what extent the person’s support needs can sustainably be met by family, friends, or the wider community; and to what extent the state is required to meet these needs. For someone living independently or at home with his or her family, the cost of a typical support package (day services, supplemented by home support or respite care) is generally only a fraction of what it costs to provide a full residential support service.[[10]](#footnote-10)

FACE and interRAI collect data on such support services, and this is built into their costing formulas. RAS 5 multiplies the points total by a weighting related to the availability of help from family and friends.[[11]](#footnote-11)

The SIS instrument does not collect any information on support available from family members so this would have to be collected separately in order to develop a costing formula using SIS.

# 1.2 Estimating costs from needs assessments

## Develop own costing formula, or use off-the-shelf system?

A basic choice is whether to derive an Irish formula from first principles that would translate needs assessments into corresponding budgets, or to adopt an existing formula, tailoring it to the Irish cost base.

Each of the assessment tools studied ranked service users in broadly the same order. Therefore, in principle it could be possible to use any one of the assessment systems as the basis for a home-grown formula to convert needs into a corresponding budget requirement. There would however be major work involved to develop a robust original resource allocation formula for Ireland. It would require a large and fully-representative sample of assessments so that the formula derived from this data would be valid and generalisable to others.[[12]](#footnote-12)

The advantage of starting with a ready-made formula from another jurisdiction is that initial testing and formula development has already taken place on a large sample of service users, and the cost formula has undergone successive revisions to improve its accuracy as more data became available. It is easier to modify and refine an established system as data becomes available when it goes live, than to start with a blank page.

Therefore National Disability Authority’s advice is to begin with a well-developed resource allocation model from another jurisdiction that offers a ready-made formula to convert assessment scores into costs/hours of care support. The formula should be adjusted to reflect differences in wage rates in Ireland. When the system is put into practice, as data from Irish assessments becomes available, the formula should be recalibrated and fine-tuned. Using a ready-made system would also enable an earlier start to be made in introducing a resource allocation system linked to needs.

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| --- |
| **How to derive a formula to convert assessments to budgets**There are two basic methods for constructing an original costing formula. One or other of these approaches underlies the costing formulas used in other jurisdictions. Each method relies on having assessment data on a large initial representative sample of service users. For accuracy, it is important to include a large sub-sample of service users with high support needs, who will account for a significant fraction of the overall budget. The relationship between assessment scores and budgets that is established for the representative sample is then assumed to be reasonably valid for any other service users. Method 1 – Derive a statistical relationship between assessment scores and current costs* Where the current costs of the services is known for a large representative sample, statistical techniques are used to calculate a mathematical relationship between the assessment profile and the corresponding cost of services. Techniques used could include cluster analysis (InterRAI) or statistical regression (SIS). When current expenditure on services is used as the basis to derive the mathematical relationship, this runs the risk of importing any existing biases in how resources are allocated.

Method 2 – Price the basket of services needed, and link to the assessment scores* Score a large representative sample of service users using the assessment tool. A panel of experts agree the support hours that each individual in the sample would require. These hours are priced at an appropriate rate, and overhead costs added on. Match assessment scores to bands of cost, and use to derive a formula to link scores to cost. (Examples FACE, some English councils)

Relationship between costing formula and total budgetCosting formulas that are based on pricing the basket of services required are good for ensuring that an individual budget is adequate for a person’s needs, but are not constrained to total to the budget available for services. Waiting lists can emerge as a result. [[13]](#footnote-13) Costing formulas which are based on establishing a mathematical relationship between measures of support needs and current spending should in principle aggregate to the total budget for disability services, provided the sample on which the formula is based is truly representative and the current costings used to derive the formula are accurate. These statistical approaches are good at apportioning existing resources fairly and equitably according to need, but may not guarantee that individuals’ needs would be met in full. A points-based system, however the points are derived, can be constrained to match total budget. The Arduin organisation in the Netherlands has apportioned budgets between different service users in proportion to their standardised SIS scores.[[14]](#footnote-14) Matching percentiles of budget to percentiles of scores, as recommended by In Control, is another way to apportion a given budget. |

Appendix 4 sets out in more detail how the formulas associated with each of the four assessment systems was derived, along with the systems used in a number of English local authorities visited by the NDA.

### Off-the-shelf cost formulas

Two of the systems studied, FACE, and interRAI come with ‘off-the shelf’ conversion systems which could translate the personal profile information into corresponding costs, albeit based on information from other jurisdictions. However, it would be fairly straightforward to convert the budget figures generated from such formulas into equivalent hours of support, and to reprice those at Irish wage rates.

FACE has a cross-disability assessment system that could be implemented straight away, and an associated algorithm to convert individual profiles into budgets. InterRAI does not as yet have an integrated cross-disability assessment. It has a well-developed resource allocation systems for nursing home care and for home care. InterRAI developed and tested a resource allocation system during 2014 for its intellectual disability assessment tool.

## Ease of use

It is important that any instrument chosen is easy to understand, use and is straightforward in its calculation of resources. An instrument that does not meet these criteria is likely to face opposition to its roll out and use. Three of the tools have the potential for sophisticated analysis and data storage (SIS, FACE and interRAI). The security and anonymity of data which is processed by a third party is an important consideration. The fourth tool, RAS 5, does not have an external provider to calculate resource costings, and as such, security of data held by a third party does not appear to arise.

# 1.3 Accuracy of the costing formulas

There are a small number of published studies which look at the accuracy of the costing formulas associated with different systems to predict needs.

This literature uses different measures of comparison and different statistical tests for accuracy to assess individual systems, so that the results cited in the literature are not directly comparable across the different systems.

In practice, accuracy will depend not only on the technical properties of the cost formula, but also on how accurately and independently the underlying assessments have been undertaken.

## FACE

A peer-reviewed publication, from the Director of FACE and two University of London academics, reports on three separate studies using FACE

* a London borough sample of 65 older persons
* a full recalibration sample of 281 older persons from the same council
* a rural council sample of 210 cases

This publication compared the budgets produced by the FACE formula (indicative budgets) with the budgets produced after detailed individualised discussions (final personal budgets).[[15]](#footnote-15) The paper showed that for the three separate samples the indicative budgets produced by the formula clustered fairly closely to the actual budgets derived for the same individuals from a process of detailed service planning. The first study reported on in the paper showed significantly more accurate results for FACE than for the In Control RAS budgets for the same population.

The correlations between indicative and final budgets were improved when the researchers adjusted the data to standardise the care package costs to remove variance in hourly rates charged by local service providers, to remove cases where historic care packages were not representative of needs, and check and correct the data entered for assessment scores and care packages. The third study, the sample of 210 cases from a rural authority, reached a correlation of 99% after a four-stage correction process.[[16]](#footnote-16) That said, there remained some dispersion around the central value of broadly equal indicative and final budgets – 74% of final personal budgets fell within 10% of the indicative budget and 3% of final budgets were over 50% above or below the indicative budget.

Slasberg and Beresford (2014), in a critique of this paper by Clifford et al, cite two separate studies which had examined relationships between indicative and final personal budgets for a number of English councils. Three of the councils whose data was used in either study had been using FACE; however data for the FACE councils had not shown any more accurate results than councils using the In Control RAS ‘pounds for points’ system.**[[17]](#footnote-17)**

## InterRai

A number of large-scale studies, mainly in the area of nursing home care, have been conducted on the accuracy of the interRai system in predicting costs.

A large-scale study in the US, named the STRIVE project, which covered over 10,000 nursing home residents in 205 nursing homes in 15 states, compared the cost of actual staff inputs over a 48-hour assessment period with the outcome of interRai cost assessments for both the RUG III (44 resource user groups) and RUG IV (66 resource user groups) formulas. RUG III explained 30% of the variance, and RUG IV 42% of the variance in nursing inputs.[[18]](#footnote-18)

Another study from the STRIVE project looked at the accuracy of the RUG III system for persons with intellectual disabilities in nursing homes. This found that the RUG III system explained a third of the variance in the weighted time, i.e. nursing minutes, of supporting people with intellectual disabilities in these settings.[[19]](#footnote-19)

The interRAI website states that the long-term care facility RUG-III algorithm explains about 55% of variance in resource use. It states that the RUG-III/Home care algorithm explains 33.7% of variance in resource use.[[20]](#footnote-20)

The reimbursement system for nursing home care in the US using interRai is based on self-assessment by the homes themselves. This may provide some incentive to overestimate care needs, and therefore budgets – however the use of interRAI for quality control purposes may offer a counterweight. However, self-assessment is not an intrinsic feature of the interRAI system.

## RAS 5

The recommended system from In Control for converting RAS scores into budgets (‘pounds per points’) has some logical flaws which affect its accuracy for resource allocation. The points awarded are additive, which implies that if someone has both supervision needs and direct care needs, additional hours of support would be costed in to assist with dressing etc. on top of simultaneous support hours for supervision.

Thom (2010) points out that the system with RAS 5 to match percentiles of cost with percentiles of score can result in a jagged rather than a smooth relationship between successive points scores and the corresponding budget.[[21]](#footnote-21) At certain points along the distribution, the budget generated may be highly sensitive to differences as small as one point. As a result, the budgets generated could be highly sensitive to how accurately questionnaires are completed or scored, and to judgments made about how needs are scored. NDA simulations done on data from our field trial also showed the phenomenon of dramatic changes in predicted budget for a minor change in the scores as between individuals.

Research by Slasberg and colleagues (2012) appears to bear out poor performance of In Control’s RAS system in accurately predicting needs.[[22]](#footnote-22) Slasberg’s method analysed the gap between the predicted indicative budgets using the formula from the resource allocation system with subsequent actual personal budgets developed from a detailed examination of the individuals’ needs. An examination by Tyson in 2009 of over 500 cases in Hartlepool, which uses a variant of RAS 5, had showed the predicted average indicative budgets using the resource allocation formula were 1.08 times the actual personal budgets following detailed examination. However, Slasberg et al.’s analysis showed that this relatively close match between average values concealed a very wide spread of diverging results between indicative budgets predicted by the RAS and actual budgets. There was no clear central tendency towards the values predicted by the RAS and the actual personal budget to broadly coincide. In an analysis of data from 512 cases from Hartlepool in 2012, Slasberg et al. showed the difference between indicative budgets and subsequent actual budgets varied by an average factor of 3.84. That paper also analysed data on over 5,000 service users in three English councils which showed a similar wide dispersion between the values generated by the RAS formula and the final budgets, and no general tendency to coincide.

## Supports Intensity Scale

The Supports Intensity Scale is typically used in conjunction with other information including information on family support, on challenging behaviour, and on local cost variations, to derive a relationship between scores and cost. The disability service authorities in Washington State improved the prediction of residential support needs when they added items to the SIS around sleep patterns, seizure control, ability to apply prescribed treatments/therapies, diabetes management, amount of protective supervision, and additional questions on problem behaviours.[[23]](#footnote-23) SIS scores alone may explain about 30% of the variation in cost between individuals. One study for Colorado showed that the best alignment of SIS variables explained 52% of the variance in residential habilitation reimbursements.[[24]](#footnote-24) Another study, presented in an appendix to the that paper, showed the contribution of the different elements of the SIS explained just under 19% of the variance in expenditure, the residential setting explained 29% of expenditure, and 52% was unexplained. With regard to the high proportion of the variance which was unexplained, the authors stated ‘this result is no better or worse than other states where HSRI has worked and where they are wrestling with aligning waiver reimbursement (i.e. funding) with individuals’ support needs’.[[25]](#footnote-25)

## Conclusion – accuracy

The evidence cited above comes from a relatively small number of studies and the criteria to assess accuracy were not the same across each system. However, White et al (2002) make the point that the correlation coefficient (R2) is equivalent to the percent of variance in costs explained by the case-mix classification system.[[26]](#footnote-26) Therefore some comparison can be drawn between the correlation achieved by the FACE algorithm, and the proportion of variance in resource hours explained by interRai’s Resource Utilisation Groups, albeit that the underlying concepts being compared may be somewhat different. The available evidence points to the FACE system as the most accurate of the four in predicting costs or budgets.

InterRai is the next most accurate system.

On its own, SIS would show poor explanatory power because it doesn’t explicitly capture family support or residential circumstances. RAS 5-type ‘pounds for points’ schemes have a poor track record in accurately forecasting support costs.

If the primary purpose of introducing this system is to support more equitable resource allocation and to lead to the introduction of individualised funding or personal budgets, then accuracy will be a key criterion in choice of system.

# 1.4 Technical psychometric characteristics

This section considers the reliability and consistency of the individual assessment tools. There is an appendix that outlines the technical characteristics of each tool in more detail (Appendix 2).

Comparing the tools is not straightforward as not all the tools were tested to the same extent, on the same domains, nor using the same statistical techniques. Therefore, a clear cut ranking of the tools technical characteristics is difficult (see Appendix 2 for details). A previous NDA paper[[27]](#footnote-27) has highlighted that all four tools measure care needs and are therefore valid. All tools are suitable for people with different types of disability; however editing would be needed for SIS and interRAI. RAS 5 has not conducted tests on reliability and validity. FACE has conducted some testing but this has not been published in peer reviewed journals. Both SIS and interRAI have conducted extensive testing and this is published in peer-reviewed journals (see table 1).

FACE has an in-built facility to check for consistency between the responses to different questions. For instance if someone replied that they needed help to transfer but that they could use the toilet without help, this generates a query to check the responses to both questions.

**Table 1: Comparison of support need assessment tools on key psychometric variables**

| **Psychometric test** | **FACE** | **InterRAI** | **RAS 5** | **SIS** |
| --- | --- | --- | --- | --- |
| Tool appropriate to all types of disability | Yes | Yes but some question as to reliability of mental health measures  | Yes | Yes but edited version needed for people without an ID |
| Tool’s most tested domain | Mental health | Eldercare | n/a | ID |
| **Internal reliability** (consistency between a person’s ratings on related items of the tool) | Yes. Not peer reviewed | Yes  | No evidence found  | Yes |
| **Inter-rater reliability** (consistency between administrators’ ratings of the same person) | Yes. Not peer reviewed  | Yes  | No evidence found | Yes  |
| **Test-retest reliability** (consistency between a person’s ratings over two or more different time periods) | Yes. Not peer reviewed | Yes  | No evidence found | Yes |
| **Content validity** (degree to which professionals agree that the full construct (support need) is measured by the tool) | Yes for mental health | Yes  | No evidence found | Yes  |
| **Concurrent/Criterion-related validity** (consistency between a person’s rating on the tool and similar measures or clinical judgement of professionals) | Yes for mental health | Yes  | No evidence found | Yes |

To summarise, comparing the technical characteristics of the tools is difficult because the tools are not tested to the same extent, on the same domains or using the same tests. FACE has not published peer review evaluations, however internal FACE papers do show good statistical properties.[[28]](#footnote-28) InterRAI has the most testing, particularly for eldercare and this shows good reliability, validity and consistency. SIS has published evaluations for its intellectual disability tool that has good statistical properties. We could find no published statistical tests for RAS 5.

# 1.5 Flexibility in use off-site

The tool chosen should be user-friendly and should support mobile working. This means that staff are equipped with appropriate technology to allow them to securely access the appropriate database when they are away from their offices. This can increase the amount of time that staff can spend in direct contact with the service users and maintain accurate recording. This approach also means that the different stages within the process of assessment (resource allocation; financial assessment; support planning; service purchasing and review) can be undertaken more efficiently.

Against the need for ease of use and easy uploading is the need for security of information. Any chosen system would need to conform to relevant data transfer protocols and the Data Protection Acts 1988 and 2003.[[29]](#footnote-29)

### FACE

Users can complete FACE either on a paper copy or on a writable PDF. The data from this PDF is then automatically unloaded. The FACE licence includes access to a centralised data collection and budgetary calculation web service, making it very easy to deploy. Users only need internet access in order to make use of the system, and need no local installation of specific software. The assessment tools have extensive software support. Updating of the system, to account for policy changes or budget changes, is done centrally, therefore updates are universally available.

FACE is collected on simple devices in an offline format and then uploaded to FACE for calculation. It offers a complete information technology solution from the collection of data to the calculation of resource allocation. Security protocols would need to be adhered to for this data transfer and storage.

FACE also have versions of the tool in 'machine-readable' formats, such as XML, which they supply to vendors to facilitate its implementation. FACE report that the vendor licence is non-onerous. However, vendors are required to implement the tool in such a way as to enable export of the data for analytical purposes.

### InterRAI

InterRAI is designed to work on the platforms produced by licensed software vendors who pay a royalty to the interRAI organisation. Any contract with a software supplier would need to ensure that it could work offline and that security protocols meet national standards. The cost of this software depends on client requirements and proposed usage and would need to be negotiated with the supplier. Full value of the interRAI isrealised when the electronic format is used to collect data. Associated software allows accumulation of client data over time, automation of assessment triggers and calculation of resource utilization groups (RUGS) can be compiled automatically.

### RAS 5

Among all the tools RAS 5 is the easiest to use – it has the simplest form and can be completed offline and uploaded later. The conversion of scores into a cash allocation is simply a Euro per point calculation (see above). RAS 5 is a paper-based system but it would be relatively easy to create a portable spreadsheet. More difficult is a system to automate comparisons and calculate resource offers as these would need to collated and, at the time of writing, there is no facility to do so. Security of information does not arise as there is no centralised collection of data.

### SIS

SIS users complete the form on line and upload the data to a centralised database. It is not clear how well the system works off-line. The contracting authority needs to check that SIS information meets with satisfactory data protection standards.

# 1.6 Copyright

### FACE

The license fee to use FACE includes rights to use the tool in both paper and electronic formats. Changes in order to localise the tool are permitted only with FACE permission. The latter condition is to ensure the integrity of the tool remains intact and to keep FACE abreast of changes. (With regard to any required changes FACE advise that these are undertaken jointly with FACE since there may be broader implications of substantive changes; and even minor changes can affect formatting across the whole document.) FACE report that they expect minor changes such as aligning terminology with locally-preferred terms or identifiers.[[30]](#footnote-30)

Additionally, software vendors for FACE are required to pay FACE an annual electronic reproduction fee which covers FACE support to vendors in implementing the tools electronically. For example, if Ireland purchased a national licence but had a preferred software supplier other than FACE, then the software supplier would need to be licensed by FACE to reproduce it.

### InterRAI

The interRAI website states “Use is permitted only by written license with interRAI; the purchase of a User’s manual does not provide a user license. However, non-commercial users (e.g., governments, care providers, or researchers) are **generally** granted a royalty-free license” (emphasis added [http://www.interRAI.org/licensing.html](http://www.interrai.org/licensing.html)). The royalty-free licence comes with some clauses (the following comes from the interRAI website):

* the instrument is not to be changed substantially (excepting individual identifiers and demographics), although additional items can be added
* only licensed translations can be used
* the instrument will not be incorporated into products to be sold to or paid for by others
* the organization will make appropriate efforts to inform others of the copyright status of the instrument
* interRAI's logo and copyright notice are to appear on the form and any other publication
* authors, author institutions, and translators (as appropriate) are to be acknowledged in any document where authors would usually be listed
* electronic data from use of the instrument are to be shared with interRAI, subject to existing laws on confidentiality and data use.

A report written for the U.S. Department of Health and Human Services[[31]](#footnote-31) highlights “IP issues with respect to the RAI/MDS are complicated because the assessment instrument and data set have always been considered to be in the public domain, but only in the United States. Beyond United States borders, interRAI claims rights to version 2.0 of the RAI and MDS, and use of the RAI/MDS requires a license agreement with interRAI. IP issues are further complicated by the fact that the 1995 edition of the user's manual for version 2.0, written for and with HCFA, has been copyrighted by interRAI with the U.S. Copyright Office, which is unusual for a work considered to be in the public domain” p11.

The other instruments for assessing people across the continuum of care, for example home care, assisted living, palliative care, and acute care, appear to be solely the intellectual property of interRAI, and their use subject to licensing agreements with interRAI. InterRAI has promoted the complete set of assessment instruments as suitable for assessing all post acute care patients.[[32]](#footnote-32)

The report highlights an issue about the intellectual property of scales based on the interRAI. Copyright information on the interRAI web site includes the statement: "The scales, algorithms, and case-mix measures based on these assessment instruments cannot be copyrighted and are thus available to everyone (although the individual items on which they are based are usually copyrighted).” The report argues that

“Presumably, this refers to scales created by interRAI, since LTCQ, Inc. claims ownership rights to the Cognitive Performance Scale (CPS), a well-known scale based on the MDS. It is unclear whether claiming copyright to the MDS-based CPS is in direct conflict with the terms on the interRAI web site. LTCQ, a consulting company formed in 1992 by other participants in the HCFA MDS contracts, has patented or trademarked Data Integrity Audit, Performance Portfolio, RiskRx, and Q-Metrics. In addition to the CPS, LTCQ claims copyrights to the Pain Scale (PS), Pressure Ulcer RAP Items [scale], Pressure Ulcer Risk Model [scale], Depression Rating Scale (DRS), and the Social Engagement Scale, all of which are based on v.2.0 MDS data.” p 13.

### RAS 5

In Control literature makes no mention of copyright or licences.[[33]](#footnote-33)

### SIS

The SIS by AAIDD is a copyrighted and registered trademarked assessment tool.

# 1.7 Roll-out and practicalities of introduction

There are several important steps in the roll out of a resource allocation tool. The National Disability Authority is undertaking further research to inform practical implementation issues drawing on the experience of other jurisdictions, and further more detailed advice will follow when that is complete.

## Critical issues for implementation

The objective of implementing a resource allocation tool is to have transparent, fair procedures but there are many ways this can be achieved. Critical issues include:

* who administers the tools
* how often is the questionnaire administered
* who owns the data
* how is quality assurance provided
* how is the process audited
* who is covered by the resource allocation system
* where, or with which groups, should the process of roll-out begin

How each question is answered has a bearing upon the other questions. For instance if the tools are administered in-house by service providers, there may be an incentive to inflate responses. Therefore the need for auditing becomes more critical. Equally if the tool is administered by external agents they may not be fully aware of the complexities of an individual’s position and therefore the ability to request a re-evaluation becomes critical.

One of the important findings of the NDA field trials was the importance of triangulating responses, with self-assessment and the views of the family or the key worker cross-checked against one another. This is a safeguard against under- or over-statement of a person’s functional capacities and needs.

The NDA field trials were undertaken by a group of trained assessors working in disability services who carried out assessments in a different service. This gave a combination of disability and assessment tool expertise, along with independence of the assessment from the service provider. While there are some logistical arrangements associated with this approach, it might present a useful model to follow.

## Information ownership and data protection

Whoever is charged with collecting the data, the NDA envisages that similar arrangements to the HRB’s Disability Databases would apply to the assessment data. Ownership of the data would be vested in the HSE or Department of Health, and data with appropriate PIN numbers would be held centrally. Access by individuals to information about themselves and to request amendment of inaccurate data, as provided for under the Data Protection Acts. There would be similar protocols on data protection and keeping information safe and secure. Anonymised data would be used for service planning. There would be similar protocols to regulate access to the data for bona fide research purposes.

Equivalent safeguards would need to be in place with regard to any agreement with a third party to process anonymised data.

## Staged process

Rolling out standardised assessments will be a staged process. The National Disability Authority advises that initially the single assessment tool should be administered to people at points of transition, such as people transitioning from congregated settings into the community, new applicants for personal assistance services, school leavers applying for day services, people leaving rehabilitation training and seeking day support, and people moving into a residential service.

So, for example, a resource allocation assessment might guide the resources to be allocated in respect of an individual moving from a congregated setting to the community.

Before the system would be used to allocate resources in respect of those service users who are not in transition, consideration might be given to calculating ‘shadow’ allocations which would provide information on the resources individuals or service providers would receive if the resource allocation system were fully in place.

The proposed implementation of Money Follows the Patient set out in Future Health suggested that initially 20% of an organisation’s funding would be based on the new funding formula, and 80% on the current system, rising in 20% increments until the new system is fully in place.[[34]](#footnote-34) A similar staged approach may be appropriate for introducing a new resource allocation model for service providers. There are risks however in drawing out the transition process over too long a period – other jurisdictions have found that winners take their gains quietly, but losers may exert strong pressure which potentially jeopardises the implementation timetable.

## Implementation group

The NDA advises that a separate implementation group be set up to drive implementation of the single assessment and resource allocation system.[[35]](#footnote-35)The implementation group should be supported by an advisory group which includes, among others, service users, families and service providers.

While elements of implementation should be explored by an implementation team several issues should be born in mind.

* Time is needed to get service users and service providers familiar with resource allocation and to understand the benefits of standardisation of resource allocation. Initially the investment in training and time might be seen as an additional overhead but is critical to the efficient and effective long run operation of any resource allocation system.
* While regular reassessments have the advantage of being up to date and accurate, they also impose administration costs and burdens on service providers. Therefore, for people with stable disabilities, reassessment about every three years is probably optimal.
* Service users should be able to trigger reassessments easily.
* Assessors from outside the person’s services should do the assessments but these should be agreed and signed off by the relevant service provider.

Part 2 – Wider uses

This section looks at the possible wider uses of the different systems in addition to the resource allocation focus. This suitability for wider use is a key consideration in the choice of the optimum system. Key questions posed by the Department of Health were

* the suitability of tools surveyed to fit into the planned overarching service delivery framework
* inter-operability of support systems and information tools especially the interface with eldercare
* support for development of a methodology to link assessments made with outcomes achieved
* support for integrated assessments for other areas e.g. income support, education and training, or employment activation
* support for implementation of the Part 2 of the Disability Act
* service planning
* quality assurance
* auditing and accountability

In broad terms, there are three systems which collect more detailed profiles on the individual (FACE, interRai and SIS) and one which collects limited information on the individual (RAS 5). The three systems which collect more detailed data have greater potential for wider use beyond the resource allocation function.

## Use of a common assessment tool brings benefits

Whichever system is chosen, there would be wider benefits to the disability service system from having a common assessment tool; a common measure of expected resource costs; and a common way of recording service user profiles across all disability types (physical, sensory or intellectual disability or autism), all service providers, and all regions.

Having a common assessment tool would facilitate overall service planning, and enable like-for-like comparisons to be made between different providers. Common terminology and data would enable aspects such as costs, staffing, skill mix, and services offered, to be compared between different providers.

# 2.1 Overarching service delivery framework

Services for people with physical, sensory or intellectual disabilities and autism are part of the Social Care directorate of the HSE which covers disability and eldercare. Disability has its separate budget. Service delivery, as set out in **Community Healthcare Organisations – Report and Recommendations of the Integrated Service Area Review Group** is via nine Community Healthcare Organisations encompassing 90 primary care networks each serving a population of approximately 50,000. Within each Community Healthcare Organisation (CHO), local Directors of Disability and Directors of Older Persons’ Services will work with local Directors of Social Care. The Review Group envisages that the new CHOs will enable and support integrated care, enable integration of services to a local population, and standardise models and pathways of care.

About 80% of funded disability services are delivered via NGO providers, and about 20% via HSE services, with a small element of private delivery. The terms of service are set out in service level agreements with individual providers.

## Commissioning

The reform programme in disability services envisaged a move to a strategic social care commissioning framework.

As set out in the National Disability Authority’s paper on a commissioning framework for disability services, the starting point for any commissioning process is a national needs assessment system that would generate adequate data to inform service planning and the specification of service requirements.

So it would be an important building block in specifying the services to be commissioned to have current and potential service users profiled to a common template. This would enable aggregate support needs at national and local level to be identified in a consistent way.

# 2.2 Interoperability in Social Care

The HSE’s Social Care Directorate covers both disability support services, and services for older persons. The older person’s interRAI instrument has been already been chosen as the single assessment tool for older persons, and is to be rolled out initially as a way of assessing people in hospital or in the community in relation to nursing home care (Fair Deal) or home care packages.

There are obvious advantages to using assessment tools from the same family, with similar language and definitions, throughout the Social Care domain. Direct comparisons could be drawn across a person’s lifespan between an eldercare assessment and any earlier disability assessments.

While all the disability assessment tools cover much of the same ground in terms of activities of daily living and instrumental activities of daily living, they differ in the formulation of the questions, and the reference period over which a person’s capacity to do things for themselves is captured. So while the profile of an individual may convey a very similar picture on two different assessment tools, it would not be straightforward to match data and concepts exactly item by item from two different tools, and the comparison would not be as nuanced as if both assessments had come from the same family of tools. The interRai software system being developed for the HSE allows a pdf to be attached to a person’s profile, which could include a scanned-in copy of any prior disability assessment using a different system. However, if prior disability assessments had not used InterRAI, they would not form a readily-linked dataset on the individual.

It should also be possible to develop a small macro (mini-programme) in Excel to export relevant data from FACE or RAS 5 in data form to the person’s InterRai file, as these are fundamentally Excel-based systems. Providing an automated export of data for the Supports Intensity Scale from SIS Online to an individual’s interRai file in data form could be a little more difficult and involve more programming. But if the relevant information can be scanned in as a pdf, the difference in usefulness would be quite minor.

While it would be convenient to use the same assessment family in both wings of the Social Care division, it would be overstating the advantages to say that the same system should be used for both.

## People with ID generally remain in disability services

Currently, the most continuous and intensive users of disability services are people with intellectual disabilities who receive full day or residential services. Generally speaking they remain under Disability Services for their lifetime rather than moving into Older Persons’ Services.

## Reassessment generally required if switching to eldercare

Older Persons’ Services support people aged 66 or over and those who have acquired a disability in old age.[[36]](#footnote-36) Where a person with a disability accesses Older Persons’ Services for the first time, this may be associated with a change in medical or social circumstances which requires additional supports. Where moving into Older Persons’ Services is due to such a change in circumstances, rather than to passing an age threshold, a new assessment would be required to reflect the change in their support needs.

## Minor benefit

The National Disability Authority considers that the convenience of linking prior disability interRai disability assessments with subsequent interRai eldercare assessments would be relatively minor.

## Same personnel for eldercare and disability assessments?

Using a common family of tools for disability and for eldercare assessments could bring about some economies of scale in training of assessors in both the interRai eldercare and the interRai disability instrument. The IT platform being built for the interRai eldercare assessment tool could be a starting point for an IT platform for the interRai disability assessment tool.

The National Disability Authority however would caution about using the same personnel to conduct eldercare and disability assessments, despite some potential economies of scale. There would be significant risk in combining the two assessment processes or assessment personnel. Chief of these is the risk of translating the medical model of care support which is associated with end of life care to the assessment of disability support needs.[[37]](#footnote-37)

While it may be a common goal of both disability services and of older persons’ services to promote living at home and to maximise independence, there are also clear differences. The focus of eldercare assessments is on supporting people with significant health needs as they approach end of life. The focus of assessments for people with disabilities is on support to live an included life in the community over a long period of years. Support services for people with disabilities living in the community should not be dominated by a medical model.

Whatever the chosen assessment instrument, differently-skilled staff whose focus is on supporting inclusion should conduct assessments of people with disabilities, If the assessments for disability are to be the responsibility of disability sector personnel, and assessments for eldercare the responsibility of the eldercare team or the public health nurse, there would be very limited economies of scale from using the same family of assessment tools for both settings.

### Hardware compatibility

Interoperability of hardware for an InterRai eldercare and an alternative form of disability assessment would only arise where the same team would be conducting both assessments. From checking with the different software suppliers, and our own experience with the field trials, standard hardware such as normal PCs, laptops or tablets could readily run any of the software involved.

FACE information can be collected on an Excel spreadsheet, and the algorithm underlying the generation of cost information is basically an Excel formula. Special software, at additional cost, is available from FACE, which can give improved outputs and management of data, however this runs on ordinary PCs or laptops, and the server requirements are standard.[[38]](#footnote-38) RAS 5 is a simple system where basic data and calculations can be done via an Excel spreadsheet, and no special hardware or software would be required. SIS Online is the software system which conducts automatic analyses of data from the Supports Intensity Scale, with data entry from normal PCs or laptops. Experience with the pilot test suggests that online data entry and processing would be the only feasible way to go if SIS were to become the chosen model.

## Conclusion

While using an instrument from the same family as the single assessment tool for older people has advantages, it does not constitute a compelling reason in itself for choosing InterRai, and any diseconomies from using a different assessment instrument for disability services would be relatively minor.

# 2.3 Measuring outcomes achieved

## Agreed outcomes framework not yet in place

There is no agreed national outcomes framework yet in place for adult disability services. However, the National Disability Authority has researched similar outcome frameworks, looking at the literature and what is being done in other jurisdictions, and has undertaken initial consultations around the following draft set of outcome goals for disability service users

* living independently in the community
* participating in social and civic life
* participating in economic life, education or training
* enjoying a good quality of life
* achieving best possible health and well-being

This section of the paper looks at how the different tools might be used to measure outcomes achieved for people with disabilities. Provision of outcome measures is important management information for individual service providers; for the Department of Health; for the HSE as funder, and in due course as commissioner of disability services; and for HIQA as the regulatory body.

Any reliable set of data on disability support needs that was collected in a consistent way could enable comparisons to be made over time and between different settings, different services, and different geographical areas. The process of measuring outcomes and comparing them across time and across different settings could be used for quality assurance purposes and to highlight any areas of poor practice or where service improvement should focus.

## Outcomes for individuals and comparisons across settings

Where information on a particular topic is collected in the basic questionnaire, changes in the answers given over time in respect of individuals could be used to track if their situation is improving, static or disimproving in relation to key areas of interest such as emotional health, physical well-being or challenging behaviour. It would also be possible to compare such outcomes across different settings – day services or residential services, institutions or community, for different geographical areas (e.g. Community Healthcare Organisation regions) or for different service providers or individual services.

When comparing two groups it is important to understand how the groups are similar and dissimilar. For example, one group may consist predominantly of people with low to moderate support needs, and another group may be predominantly those with severe to profound levels of disability. When comparing outcomes across different groups, it is necessary to adjust for differences in the composition of the groups. There are standard statistical techniques that can do that.

## Supplementary questionnaires could be added to any system

Where information on particular outcomes of interest is not already included in a questionnaire, in principle it would be possible to add supplementary questions to do that, provided the analysis software could be adjusted to process the additional questions. Arduin, a service provider in the Netherlands, has added a quality of life assessment instrument to the standard SIS assessment, and used the combined output to inform the individual’s service plan, along with developing a Personal Outcome scale based on eight core quality of life domains.[[39]](#footnote-39)

## All can track changes in overall support need scores

Any of the four systems could track a reduction in overall support required by individuals, for example as a result of a particular intervention – such as provision of rehabilitation, of assistive technology, of behavioural support, or a change in living circumstances. Therefore any reduction in support costs could be related to the cost of the intervention, to measure the financial payback.[[40]](#footnote-40)

### InterRai, then FACE have more items of relevance built in

Because RAS 5 only collects information on nine items, it is of limited value to provide any wider outcome measures without an add-on suite of additional questions. Of the other assessment questionnaires, interRai, followed by FACE, has the most items built-in that could be used, without further addition, for measuring outcomes.

## FACE items relevant to outcomes

A number of items on the FACE questionnaire signal aspects of well-being that can be tracked for individuals over time, or compared across settings. These measures include questions on unaddressed health and health promotion needs; on medication; on pressure ulcers; on emotional well-being; on abuse/neglect; and on isolation. There are open questions on social activities and relationships, and on work, education and training, with the answers in free text. The person is also asked about any concerns they have with the quality of care they currently receive.

## InterRai items relevant to outcomes

The interRai questionnaire collects detailed information around health, including items like medication and pressure ulcers, and emotional wellbeing that are also in FACE, but it covers a more detailed range of health topics than FACE.[[41]](#footnote-41) While FACE records a person’s social network and valued social relationships in free text, InterRai records the strength of social relationships and frequency of social contacts in a way that would make comparisons between groups or over time easier to track. InterRai also records employment status.

## SIS language less useful for measuring outcomes

Because of the way its questions are formulated, the SIS questionnaire has a more limited potential to capture changes in individual aspects of well-being. It asks about the frequency, duration and intensity of support required for different aspects of life, and whether or not the individual is currently doing the relevant activity. As such, it doesn’t record whether or not an individual, for example, ever visits friends or family, just the support they might need to do so. In Utah, this limitation has been overcome by recording in addition how important the different listed activities in the questionnaire are **to** the person.[[42]](#footnote-42)

## Challenging behaviour – FACE, InterRai and SIS collect

Providing environments and supports that help minimise challenging behaviour and its triggers is important for the quality of life of service users. FACE, InterRai and SIS all record challenging behaviour, which could enable changes in the incidence of this over time for individuals or across different settings to be tracked and analysed.[[43]](#footnote-43)

## Conclusion

InterRai builds in the most items into its questionnaire that are relevant to service outcomes. The next most comprehensive assessment is FACE.

A resource allocation assessment is generally a conversation between an assessor, the person with a disability, and their family or key worker, in which certain items are formally recorded on the standard questionnaire. Some topics of interest to outcomes measurement may form a standard part of that conversation even if not formally recorded on a particular questionnaire, but others may not emerge without prompting. Adding a supplementary set of ‘outcome’ questions to the standard assessment would be a practical option if so required.

# 2.4 Using the assessment to guide other entitlements

How useful could the information gathered through a resource allocation assessment be in informing applications and eligibility for other disability-related entitlements, such as education and training, employment activation or social welfare payments?

## Collect once, use often

There is merit in a ‘collect once, use often’ approach to basic information about a person’s disability status. This would need to be supplemented by additional assessment and information appropriate to the particular scheme in question.

Assessing and verifying basic information just once can lead to efficiencies for individuals making applications for services, and for medical and other personnel who are currently required to fill in repetitive forms. There could be gains in efficiency for the agency processing requests for services, provided any data protection issues about information sharing are addressed, and the agencies’ systems are able to recognise or accept data collected for another purpose.

Where a single assessment could give rise to multiple entitlements, the reliability and independence of that assessment is key. Any incentive to upcode, in other words, to record a higher level of dependency for resource allocation purposes would be magnified where multiple benefits are riding on the single assessment.

Eligibility for most disability-related schemes requires certification by an appropriate professional, e.g. a doctor, a psychologist or an occupational therapist. In practical terms, the question of who signs off on the assessment may count for more than the content of the different assessment tools in determining how useful they could be for qualifying for other entitlements.

## Elements in assessing eligibility

Most schemes have two separate elements in establishing eligibility

* evidence of a disability, the associated functional difficulties and their severity
* specific criteria relating to the relevant scheme, e.g. educational difficulties or employment capacity

As any of the resource allocation tools can distinguish between levels of support need, ranging from minor to moderate to exceptional, they all would have some relevance to the first criterion. The NDA’s research has shown that any of the four tools will produce a broadly equivalent ranking. A composite score on any of the tools may be useful in triaging those with low support needs. Such scores may offer broad guidance on whether someone is above or below thresholds of eligibility set out in law, but were not designed with that end in mind.

The resource allocation tools are not designed to collect information about scheme-specific criteria such as learning styles or difficulties, or capacity to work. However, they could inform whether personal support for care needs or supervision would be required in an education or a work setting.

Having high support needs and having diminished capacity in another dimension such as capacity to learn or to work, are not identical concepts,[[44]](#footnote-44) although for some people they may overlap. For example, the focus of eligibility for Domiciliary Care Allowance is on care needs (having care needs that are substantially in excess of a typically-developing child of the same age). Eligibility for Disability Allowance is based on having a diminished capacity to work.

The four assessments have graded levels of detail, from the simplest, RAS 5, to FACE, to SIS, to InterRai. The degree of complexity or fine-grain of detail required for eligibility for other services would determine which was more useful in the particular context, but it is probable that the degree of information contained in the latter three would be well beyond what is likely to be required to establish a general threshold of disability or support need.

In effect, there is no clear winner under this particular heading.

# 2.5 Support for implementing Part 2 of the Disability Act

## Legislation

Part 2 of the Disability Act provides for independent assessments of need. ‘Assessment’ in this context is defined in section 7 as

An assessment to determine, in respect of a person with a disability, the health and education needs, if any, occasioned by the disability and the health services or education services (if any) required to meet those needs.

‘Health service’ in this context is defined as a service (including a personal social service) provided by or on behalf of the HSE. Under the Act, education assessments are referred to the National Council for Special Education (NCSE). The NCSE’s role under the Education for Persons with Special Education Needs Act 2004 in conducting assessments has not yet been commenced.

There are HIQA Standards for conduct of Assessment of Need drawn up under s. 10 of the Disability Act 2005.

### Only commenced for those born from 2002 onwards

Currently, the independent assessment of need process is in place for children who were aged under five in June 2007, in other words children born after June 2002. Those assessments currently focus on the disability services most accessed by children, such as therapy supports, special pre-schools, assistive technology, and respite care. Only a very small number of children receive a residential care service.

## Which elements of assessment can resource allocation tools do

Any of the four resource allocation assessment tools for adults would be able to identify a major element of the ‘health and education needs occasioned by the disability’, namely the requirement for personal social services. They are not designed to capture the requirements for assistive technology, the level of therapy inputs required, nor the detail of medical services requirements occasioned by a disability – separate more specialist clinical assessments would be needed for these purposes.

RAS 5 has no questions that relate to therapy services. FACE in its Next Steps section has specific questions as to whether further tests or investigations, further assessment, or equipment/adaptations are required. SIS has a question on whether therapy supports are needed. InterRai asks whether the person avails of therapy supports, and also can pick up on unmet dental care needs. InterRai can also generate alerts, based on the information about a person’s physical or mental health status, for onward referral.

## Family support and its sustainability

RAS 5, FACE, and InterRai collect information on the family supports available – this is not collected in the SIS. InterRai and FACE document the sustainability or stability of the support available.

## Education

Information collected under any of the tools on support needs generally could inform whether an individual might require assistance with health or personal care in an education setting. In this regard, SIS captures some broad information under the heading ‘lifelong learning needs’. However, separate educational assessments would be required to identify needed what education supports would be required by an individual. None of the assessment tools are designed for the task of educational assessments, nor to assess education needs occasioned by a disability.

## Conclusion

Assessments carried out under the Disability Act are to be independent. An assessment using any of the four tools could be a good starting point to identify and record support needs in a consistent way across all disability service users. However, none of the assessments would fulfil in full the requirements for assessment set out in Part 2 of the Disability Act.

# 2.6 Aggregate service planning

## Information needed for service planning

The key elements needed for overall service planning are

* a profile of the population to be served
* current levels of resources and services, and unmet needs
* emerging needs

The main data now used to inform service planning are the Health Research Board’s disability databases, with separate databases for intellectual disability and for physical or sensory disability. The HRB also maintains separate information systems for mental health.

The four resource allocation assessments reviewed cover the range of impairments, whether physical, sensory or intellectual disability, or autism. FACE, interRai and SIS also collect information on aspects of mental health.

## Disability databases

The Health Research Board’s Disability Databases were established to inform service planning, the National Intellectual Disability Database (NIID) in 1996, and the National Physical and Sensory Disability Database (NPSDD) in 2002. While the two databases collect somewhat different information from those registered, and are different in how comprehensively they reach their target populations and how frequently the information is updated, they are very valuable tools for service planning. Through the unique PIN number for individuals, they constitute two sets of longitudinal data which can throw light on patterns and trends over time. Each database collects information on the profile of the individuals concerned (age, gender, diagnosis, region); services currently used; unmet need, and anticipated future need in the next five-year period. In addition, the NPSDD collects information on functional difficulties (WHODAS 2)[[45]](#footnote-45) and on participation outcomes (the Measurement of Activity and Participation).

### Coverage

The NIDD collects less information than the NPSDD on its target population, but has virtually complete coverage, and virtually all records are updated annually. Many service providers have embedded the NIDD data collection into their own software, and export the data automatically.

While it collects a more comprehensive range of information on those registered with it, coverage of the NPSDD is much less complete. Participation is voluntary. It does not cover over 65s, as their service needs are addressed in older persons’ services. Administratively, it never achieved full nationwide coverage, and data collection and updating has deteriorated in recent years with a loss of HSE administrative staff and the embargo on filling such posts. The 2014 report showed that less than a third of NPSDD records had been updated in the previous year.

## Can assessment tools add value to HRB databases?

The roll-out of any chosen resource allocation system is likely to be initially on a phased basis, and it could be a number of years before a system of assessments would be fully up and running.

The National Disability Authority’s conclusion is that the databases be retained and merged, and that a small number of additional data items, which are key drivers of cost, be included, such as complex medical need, and the presence of challenging behaviour. It is not envisaged for the foreseeable future that resource allocation assessments would be substituted for the existing databases. Resource allocation assessments, being more detailed, are likely to be conducted at less frequent intervals than the annual updates of the database.

However, each service provider, including the HSE, should operate an integrated data system, rather than separate profiles of individual service users for resource allocation and for database purposes.

### Small number of key items can accurately predict overall support need

The NDA’s pilot exercise showed that a small number of items, such as the 9 questions collected in RAS 5, can calculate overall support needs just as well as the more detailed assessments. It would not be necessary for aggregate service planning purposes to have the full level of fine detail collected in the more detailed assessment instruments.[[46]](#footnote-46)

Each of the four tools would be able to group service users into levels of intensity of support needs. From an aggregate service planning perspective, there is no advantage to any one particular tool. A small number of core items from whichever tool is chosen could be added as a minimum data set to the information already collected on the disability databases.

## Integrate the databases and extend to autism

The National Disability Authority advises that service planning could be enhanced by a merger of the current disability databases, extending their range to explicitly include service users/ service applicants with autism, and harmonising the range of data they collect. It is noted that in its 2005 review of the NPSDD, the Health Research Board had recommended moving towards a single disability database.

### Focus on support needs rather than diagnosis

Support needs rather than diagnosis as such is what drives care costs. The NIDD collects information on diagnosis (mild, moderate, severe, profound); and on whether or not there is a co-existing physical or sensory disability (but not its nature or intensity). However, it does not cover some key drivers of service need such as support required with activities of daily living, or additional support needs arising from a complex medical condition, complex physical disability or challenging behaviour.

It is noted that each of the four resource allocation assessments focus on support needs rather than diagnosis, although information on diagnosis is collected in both FACE and InterRai. Each of the four tools is designed to identify support needs around activities of daily living, instrumental activities of daily living, and wider social participation. This is very similar to the information collected for the NPSDD with the WHODAS 2.

### Can the assessment tools help forecast demand for school leavers

Every year, the HSE is faced with the task of finding support places in disability services for young people with disabilities leaving the school system. While the disability databases include information on young people in specialist settings such as special schools, and the National Council for Special Education has information on young people with special needs being supported in mainstream schools, these data are not brought together to inform future planning.

The resource allocation assessments reviewed here do not constitute a comprehensive vocational or education assessment to assess whether an individual would be able to participate in mainstream education, training or employment, with appropriate support, or would require a specialist day service on leaving school. However, data from a resource allocation tool could inform an assessment of the degree of support (e.g. personal assistance) a young person may require in further or higher education or employment, or in a day service.

A resource allocation assessment could therefore act to complement other sources of information to guide on future support needs of those entering further or higher education or day services.

## Conclusion

The disability databases already form the nucleus of a single national dataset on disability service users and service applicants.[[47]](#footnote-47) This could be complemented by an additional minimum dataset, drawn from the chosen national resource allocation assessment system, that had additional information on the key drivers of service cost. It is suggested that this be done by extending the range of information on the current databases to include extra items (e.g. supports required with activities of daily living, supports required to participate, complex medical needs, challenging behaviour), and a summary score from the assessment tool, rather than substituting the resource allocation system for the existing databases. Because a limited number of items can accurately assess support needs, it would not matter for this purpose which assessment system is chosen.

The NDA also advises that over time the disability databases would be merged to form a single database.

# 2.7 Quality assurance

The questions of quality assurance and outcomes measurement (s 2.3 above) are closely interlinked. Identifying how an agency is doing relative to the average can be a mechanism driving internal quality improvement, and a tool for external monitoring of quality.

For service providers, benchmarking what they are achieving relative to the average or to other services with a similar profile of needs is a useful tool for self-evaluation. This also can be a mechanism driving internal quality improvement.

If anonymised aggregate data on service users’ assessment is held centrally, then the performance of any centre on any measure collected in the assessment tool can be benchmarked against what the results are across the services as a whole. Appropriate adjustments would need to be made for differences in case-mix. A simple output called a ‘radar plot’ or a ‘spider plot’ can show on what dimensions of quality a particular service is performing ahead of the average or below average. For example, if service users in a particular service are shown to be significantly more socially-isolated than the average, that could be a focus for action to address that problem. Within a service, management can also review the results being achieved within different units or different regions, and this can inform service improvements.

In principle this approach can be followed using any of the detailed assessment tools, Face, InterRai, or SIS, by benchmarking a number of key elements in the assessment framework against national performance.

While none of the assessment tools reviewed were explicitly designed to map on to the wider set of domains set out in the HIQA standards, there are individual items in the three detailed assessment tools that relate to key aspects of the different domains, for example social connectedness; supports to work or participate in education; and health status.[[48]](#footnote-48)

This table presents items from the three detailed assessment tools that could be used for a quality monitoring framework for some elements of the HIQA domains.

| **HIQA domain** | **FACE** | **InterRai** | **SIS** |
| --- | --- | --- | --- |
| Individualised support and care | Support needs re social activities/relationshipsWork/education/ training | Social relationships; employment; involved in activities | Support needs for social activities, masking/keeping friends, education or employment |
| Effective Services | Satisfactory housingSmoke alarm | Home environment |  |
| Safe Services | Aggression or self-harm | Victim of assault/abuse. Aggrtession or self-harm. Recent fall | Exceptional behavioural support needs |
| Health and Wellbeing | Emotional well-beingHealth statusIndividual health items, whether or not being addressed | Mood and behaviourSelf-reported health.Very detailed list of possible medical issues e.g. pressure ulcer | Exceptional medical support needs |

The availability of standardised profiles of service users across different units they are inspecting could be a useful analytic tool for HIQA. Comparing identified support needs of individuals with supports actually in place would also be a valuable exercise to examine gaps, for example any absence of supports to enable participation in the wider community.

The InterRai organisation has developed a suite of quality indicators, covering many medical-type indicators (e.g. weight loss, dehydration) as well as negative mood and social isolation, for its eldercare suite. These can be prepared as a ‘spider plot’ to show how a particular agency or nursing home is doing relative to the average. For example in other jurisdictions, InterRai assessments have been used to track the prevalence of bedsores in different nursing homes as an indicator of poor standards of care.[[49]](#footnote-49) Other medical data collected by InterRai such as the prevalence of constipation or scheduled toileting, can be symptomatic of poor standards of diet, excess medication or poor standards of care. As the tool which collects the greatest level of medical detail, InterRai would be best of the four tools in identifying any adverse medical outcomes. It must be emphasised however, that this is only one aspect of service quality.

Ireland has moved away from a purely medical model of disability, with greater emphasis on equality, inclusion, social participation, and valued social roles. Adverse medical outcomes, while obviously extremely important, are not the only indicators of service quality.

In conclusion, standardised profiles have some role to play in quality assurance. FACE, InterRai or SIS all have broadly similar items that map on to elements of the HIQA framework, as set out in the Standards for Residential Services for people with Disabilities. With any of these tools, it would be possible to map whether the assessed needs of individuals were in fact being addressed, and to track if particular negative outcomes were stable or were diminishing over time. As the most detailed of the four tools studied, InterRai would have more items which could be benchmarked for quality assurance purposes across different services or over time.

# 2.8 Auditing and accountability

## Any resource allocation model could link resources to needs and to outcomes

A standardised national assessment that can be translated into money terms would be a useful tool to compare the use of resources by different service providers, and the outcomes being achieved for the resources invested. Provided the assessed costs are fairly accurately related to underlying needs, there would be no real difference between any of the assessment systems. FACE and InterRai can offer off-the-shelf resource costings, whereas these would have to be constructed for either SIS or RAS 5.

## Detecting up-coding or down-coding

Any resource allocation system that is based on self-assessment, whether by the individual themselves or their service provider, runs the risk of ‘upcoding’, or people recorded as having higher support needs than they have, because there would be a clear financial incentive to do so. Assessment by the funder may have an incentive to down-code, to minimise expenditure. Use of a neutral assessor can minimise such tendencies to bias.

Comparing the distribution of scores across different providers or geographic regions, may be able to detect evidence of systematic bias in either direction. A further check can be provided where there is a large international data set available for comparison. FACE, InterRai and SIS in principle can offer such international comparisons. InterRai does not as yet (early 2015) have data on a large disability population, but this is likely to change as this aspect is developed. For SIS, the main data potentially available would be in respect of people with an intellectual disability, as the instrument was designed and is mainly used with this group. In principle, it should be possible to compare a profile of FACE users in Ireland with comparable populations in the UK, but this may be an additional commercial cost.

# 2.9 Person-centred planning

The purpose of a resource allocation tool is to distil an individual’s requirements for support service to a common measure of support hours, measured in money terms. In practical terms, most resource allocation systems group individuals into cost bands, rather than every individual having a distinctly tailored cost figure. Personalisation of services is achieved through the process to allocate the resources which the budget can buy to support the individual to live a life of their choosing.

So resource allocation, which is a process to group resource needs, and person-centred planning, which is a process to individualise how a person lives their life and to marshal available supports around a life of the person’s choosing, are to some degree going in different directions.

That said, a standardised profile of the individual which documents their degree of dependence or need for support across different aspects of life is a useful background document in beginning the process of person-centred planning.

The three more detailed personal profiles – FACE, InterRai and SIS – are of potentially greater usefulness in that respect than the much more summary RAS 5.

The authors of the Supports Intensity Scale anticipated that its main use would be for individual supports planning for people with intellectual disability. SIS generates results which show how the individual’s support needs across six domains – home living, community living, life-long learning, employment, health and safety, and social – vary relative to the norm for other people with an intellectual disability and an equivalent overall level of support need. So for example, SIS results could highlight that an individual has relatively high support needs in the employment domain, which would helps put employment on the agenda in the person-centred planning discussion. The SIS needs to be combined with other information to produce a person-centred plan.[[50]](#footnote-50) In Utah, the SIS data collection is modified to support the person-centred planning process by using the SIS schedule to mark items as being important **to** the person (to realise the life they want to lead) or important **for** the person (e.g. supports with dressing themselves).[[51]](#footnote-51) The issues that are important **to** the person are categorised by their support team into background information, current goals, future goals, and not applicable, and Utah has developed a computerised case management system that can electronically transfer relevant information from the SIS into a person’s individual service plan. Utah has found this an effective structured method to document what they have learned about the person, and help bridge a gap between assessment and individual service planning,

## Structure and language

The structure and language varies across the four different assessment systems, and how the different topics are grouped. While all cover broadly the same range of domains, how those are framed can help set a tone that may be relevant for a personal-centred planning discussion. SIS and RAS 5 are laid out in more ‘person-centred’ ways, compared to either FACE or InterRai.[[52]](#footnote-52) That said, the order or grouping of the different items could be varied, and different headings introduced, without changing the fundamentals of what data is collected. The training for InterRai recommends that the assessor uses the form to record the information elicited and observed, rather than as an A to Z questionnaire to be done in strict order.

### More person-centred ordering of topics

RAS 5 begins with supports for personal care and taking meals, followed by practical activities of daily living like shopping and cleaning, then relationships and social inclusion, then communication, keeping safe and taking risks, and then participation in work, learning and leisure. The Supports Intensity Scale follows a broadly similar pattern, but with a more detailed focus on different aspects of wider social participation. It begins with identifying support needs for home living activities, followed by community living activities, lifelong learning activities, employment activities, health and safety activities, social activities, protection and advocacy activities, and finally medical or behavioural supports needed.

### More medicalised ordering of topics

FACE begins with physical health and medication, and moves on then to the domains of personal care, support for day to day activities (housework and shopping etc), mobility, social participation, finances, housing situation, psychological well-being, safety and risk, and support available. InterRai begins diagnosis and service history, followed by community and social involvement; strengths, relationships and supports; alcohol/tobacco use; home environment; communication; cognition; extremely detailed information on health conditions; independence and self-management; nutrition and eating; mood and behaviour; medications; and supports and services. InterRai’s strong medical focus could be perceived somewhat negatively if it were to distract from a social model and an emphasis on supporting people in wider aspects of social participation.

## Conclusion

The individual profile generated by a resource allocation assessment is a useful piece of data to inform and complement the process of person-centred planning, but is not a substitute for the detailed process which should take place to explore the preferences and aspirations of the person with a disability, and to prioritise and configure their supports to best deliver that. [[53]](#footnote-53)

The Supports Intensity Scale is the assessment tool which has the edge in focusing attention on the broader context of people’s lives, and it was designed specifically to support individual service planning. It is also the questionnaire which is organised and laid out in the most person-centred way.

# 2.10 Conclusion – broader uses

Many of the potential advantages for broader purposes that would stem from using a resource allocation system are related to the use of a single assessment tool for disability services, and not particularly dependent on which tool is chosen. Where a summary measure of support need is the important measure for wider planning and management purposes, it does not matter which tool is used, as all come to similar assessments of the level of need. All of the tools cover standard domains such as supports required for basic and instrumental activities of daily living, and for social participation.

Where more detailed data collected in the course of an assessment would be of value to wider planning and management, the three lengthier questionnaires have the advantage over RAS 5, with InterRai offering the most detailed of all the questionnaires reviewed.

While person centred-planning is a wider and more detailed process than a needs assessment, having a standardised assessment and profile of the individual can provide a useful starting point. The Supports Intensity Scale was considered to shade the other assessment tools in the area of person-centred planning, structured as it is to focus on participation in different areas of life such as education, work and social activities.

Overall, the analysis of broader potential did not find any strongly compelling arguments to favour one particular tool over another, but as the most detailed of all four, InterRai had a little more to offer.

Part 3

# 3.1 Summarising strengths and weaknesses

This final section synthesises the strengths and weaknesses of the four systems, and draws upon lessons learned in the earlier pilots.

## Cost

There are a number of different costs associated with introducing a resource allocation system. These include

* purchase of any new computer hardware required to conduct the assessments. However, as all the systems run on standard equipment, any new computers purchased would be available for other functions
* specialist computer software to run the system
* staff time in arranging, conducting and checking assessments, and in any travel to conduct assessments. This is likely to be the biggest single element of cost, whether priced explicitly through having external assessors, or priced implicitly through staff time foregone from other frontline service delivery
* training of staff to conduct assessments – both the cost of training courses, and the staff time to undertake the training
* customisation of materials and costing formulas
* licensing of assessment materials or other associated products

The report on NDA’s first field trial, which compared RAS 5 and SIS, found that the value of staff time in conducting assessments would be of the order of ten times the cost of paying for licences and dedicated software. The length of assessment interview was significantly shorter on average for RAS 5 than the other assessment tools. The cost of interviewer time would be roughly similar for the other three assessment systems.

The cost of any computer hardware is likely to be similar for any of the four systems.

The ‘cost’ heading below refers to the cost of licensing a particular resource allocation tool and its associated costing algorithm, and any dedicated software required to operate it.

### FACE

### Learning from the pilot study

The pilot study concluded that FACE does not have any obvious biases and was acceptable to service users. Both interviewers and service users ranked it as the most relevant tool for identifying support needs amongst service users and both groups said they found it easy to understand. FACE explicitly explores what support is available to service users from family and friends. The time the FACE assessment takes to complete compares well with the other three tools.

### Reliability in predicting cost

The NDA’s analysis of the limited number of studies available on reliability for resource allocation concludes that FACE has the most accurate system for converting assessments to budgets.

### Applicability to other purposes

Though not the most detailed of the four tools, FACE assessments can contribute reasonably towards other planning and assessment processes.

### Timeliness

FACE assessments could begin relatively quickly, and resource allocation could initially be based on a composite algorithm for care support in the UK, adjusted for the Irish wage levels.

### Training

The training for the pilot study was reasonably simple and straightforward and was inexpensive, with a trainer from the UK. FACE can offer ‘training the trainer’, and there is e-learning training available.

### IT

FACE can run on ordinary PCs, laptops or tablets. The algorithm for costs basically works off an Excel formula and is computed instantaneously. Additional software packages are available from the vendors which provide a case-management system, integrated data management and processing, and analytics. There may be merit in integrated data management on a centralised database which would make comparisons across time or across regions or services more robust. Such additional packages could add functionality that goes beyond what is required for resource allocation but may be of wider benefit in managing services.

### Licensing and software cost

FACE is a commercial product and a competitive cost offer would need to be established through a procurement process, negotiations on price and detailed discussions on what products or software support would be required. A basic Excel system would suffice for assessments and resource allocation, but greater functionality for wider purposes could be obtained by opting for additional software for case management or data analytics. Initial quotes received were for three options – basic, intermediate, and comprehensive. Depending on the support package chosen, costs for a basic package for FACE could be on a par with interRai or RAS 5. The intermediate package would cost less than SIS but the comprehensive package a bit more.

## InterRAI

### Learning from the pilot study

InterRAI correlates well with underlying need as defined as the average of all tools and it does not have any clear biases. Service users on the whole found it acceptable but people with multiple and complex disabilities did not feel that the complexity of their situation was adequately captured. As discussed in the evaluation of the pilot study, this was as result of the particular configuration used by the NDA and therefore the interRAI tool would need to be changed to overcome this problem. Furthermore, some of the questions were judged to be inappropriate in a disability service context and might need to be dropped or amended in any future iteration.

Overall service users thought the length of time the interRAI took was acceptable.

### Reliability in predicting cost

InterRai’s Resource Allocation Groups system has modest reliability in predicting cost, explaining up to half the variability in cost.

### Applicability to other purposes

InterRai, being the most detailed of the four tools, had an edge over FACE and SIS in terms of wider applicability for social care planning.

InterRai is particularly strong on medical and health information. A downside risk is that it could influence an over-medicalised focus.

### Timeliness

An integrated cross-disability assessment instrument for interRai is not yet available – NDA had to construct a cross-disability instrument for the purpose of the field trial, and there were some hitches experienced in its application.

While initial testing of a resource allocation system for the intellectual disability interRai tool has taken place in one US State with first results coming through in summer 2014, a resource utilisation group system for disability is not yet available at the time of writing.

### Training

For the NDA pilot, the training was relatively expensive and involved bringing in trainers from the US, as well as expensive training materials.

Training for using interRai assessments in older persons’ services involves four days of training plus a day’s practical assignment. An e-learning training package has also been procured. This process in older persons’ services should build up local training capacity in relation to interRai, although not specifically on a disability version.

### IT

InterRai can run on ordinary tablets, PCs and laptops. A bespoke software package for InterRai for older persons has been commissioned by the HSE and in early 2015 was undergoing user testing.

### Licensing and software cost

There is only a nominal cost for licensing the InterRai instruments. Apart from hardware requirements (which are common to any system chosen), special software or software development would be the main cost associated with this system. The HSE has contracted development of a software platform for InterRAI for older persons. If such software has a ten-year lifespan, the equivalent as an annual cost would be broadly on a par with FACE basic option, or with RAS 5.

It is not clear to what extent the development work on the interRAI eldercare system would reduce the cost of providing software to support an InterRAI disability instrument and associated resource utilisation groups for budget calculations.

## RAS 5

### Learning from the pilot study

RAS 5 correlates well with underlying average need and was the tool that was least likely to show a bias. The tool measures what support is available to the service user. The tool was acceptable to service users although some service users felt that the complexity of their needs was not covered. Although acceptable to interviewers, they thought it would have limited application outside the resource allocation context unlike other tools that collected more comprehensive information on service users’ support needs. However, service users did not express that concern.

The RAS 5 tool does ask about resources available to the service user and it probably could be altered to enable it to capture other information.

RAS 5 was quick to complete (average 33 minutes) and when the value of staff time is factored in, its national rollout costs are the lowest.

### Reliability in predicting cost

While a costing system could in principle be built from scratch from any of the four models, including RAS 5, the NDA is not confident that the recommended system with this tool would be sufficiently robust and reliable.

Some time would therefore be needed to build an alternative costing mechanism, and to test it, before this could become operational.

### Applicability to other purposes

As this tool has only nine items, it has limited applicability for any wider planning or management purposes.

### Timeliness

As there is no off-the-shelf reliable formula available, a cost algorithm would need to be developed from scratch – to develop the data to do that exercise on a sufficiently representative scale could be a source of delay.

### Training

The tool is very simple, and training is fairly straightforward. For the pilot, NDA secured a trainer from the UK at a modest cost.

### IT

RAS 5 can run on ordinary tablets, PCs and laptops. The costing formula is calculated on a simple spreadsheet.

### Licensing and software cost

The costs appear to be on a par with and marginally cheaper than the FACE basic package, and the annual equivalent of InterRAI software development.

## SIS

### Learning from the pilot study

SIS correlates well with underlying need but in the pilot people with physical disabilities did score slightly lower on SIS compared to the other tools.

Research highlighted that SIS was acceptable to service users but service users were also most likely to identify SIS as the tool that missed points relevant to them. Interviewers in nearly a third of cases felt that there were some irrelevant questions. Service users with a physical disability were significantly more likely to state that parts of the SIS questionnaire were not relevant to them and a more general concern was raised by interviewers as to the applicability of all SIS questions for service users with physical disabilities. At the same time interviewers felt that the SIS was very comprehensive in gathering information on service users’ support needs.

### Reliability in predicting cost

On its own, SIS only explains a small fraction of the total cost of delivering a service to meet an individual’s needs. In addition to what is in the SIS assessment tool, supplementary information would need to be collected, in particular on available family support, in order to generate better cost predictions. In addition to the main score generated by the SIS software, the scores on exceptional medical and behaviour schedules also need to be included. Even at that, studies suggest that at best only half the variation on costs is explainable, of which a fifth of the variation can be explained by the SIS.

### Applicability to other purposes

SIS like the other two more comprehensive instruments, FACE and InterRai, scores reasonably well, and with established use in person-centred planning.

### Training

SIS expects assessors to be graduates and requires extensive training. Inter-rater reliability can be low if training is inadequate. In the main, trainers come from the US, although the NDA used a trainer from the Netherlands for its pilot. A number of Irish service providers have competed training in SIS, so there is some local capacity.

### IT

Data can be collected on ordinary laptops or PCs. Numerical scores collected on SIS need to be converted into a ‘normalised’ score which ranks the individual relative to the scores of a representative sample of service users. While the data can be collected manually, transcribed and converted, this is a challenging task. SIS–Online is the proprietary system which does this.

### Licensing and software cost

Costs are for a per-assessment licence fee and for SIS-Online software, in addition to any training. SIS appears to be more expensive than any other system, except the comprehensive software option with FACE.

# 3.2 Comparison using weighting schemes

This section of the paper uses a scoring scheme to compare the four different resource allocation systems. The scores and the weights are not scientifically precise, but offer a basis for synthesising the relative strengths of the four different resource allocation systems.

Two different weighting schemes are used. The first one, devised by the National Disability Authority, looks at four broad characteristics – accuracy in converting scores to budgets, characteristics of the assessment tool, implementation, and capacity to support wider uses. This scheme gives the highest weighting to how well each system functions in terms of predicting costs, as this is the key focus of introducing a resource allocation system. The criteria also reflect four desirable properties of reliability, validity, applicability and practicability.[[54]](#footnote-54) The scoring is the NDA’s own, based on its assessment of how well the different systems perform under each of the criteria.

The second weighting system, shown in Appendix 3, is the one used by the HSE team in evaluating options for a single assessment tool for older persons.

Rankings can be very sensitive to changing weights and therefore should be used cautiously. Scoring using the HSE weighting scheme put interRAI very marginally ahead of FACE.

The following table scores the different criteria. The results show FACE came first, followed by interRAI, then SIS and then RAS 5.

| **Criteria**  | **Weight** | **FACE**  | **interRAI** | **RAS 5** | **SIS** |
| --- | --- | --- | --- | --- | --- |
| **Accurate budgets**  | **50** | **39** | **31** | **13** | **22** |
| Accuracy of cost formula | 40 | 30 | 22 | 10 | 20 |
| Collects information on carer support and its sustainability | 5 | 4 | 4 | 1 | 0 |
| Ease of calculating budgets | 5 | 5 | 3 | 2 | 2 |
| **Characteristics of assessment tool**  | **15** | **12** | **11.5** | **12** | **12** |
| Evidence on reliability and validity of instrument | 5 | 4 | 5 | 2 | 5 |
| Ease and time to complete | 5 | 3 | 2.5 | 5 | 3 |
| Cross-disability focus and language  | 5 | 5 | 4 | 5 | 4 |
| **Implementation**  | **15** | **12.5** | **10.5** | **12** | **12** |
| Questionnaire ready for use | 5 | 5 | 3 | 5 | 5 |
| Cost of using the instrument[[55]](#footnote-55) | 5 | 3 | 5 | 5 | 3 |
| IT support | 3 | 3 | 3 | 0 | 3 |
| Length of training | 2 | 2 | 1.5 | 2 | 1 |
| **Wider uses**  | **20** | **15.5** | **17.5** | **2** | **10** |
| Outcome measurement and quality assurance  | 10 | 8 | 9 | 2 | 5 |
| Triggers for actions/follow-up | 3 | 2.5 | 3 | 0 | 1 |
| Person-centred planning | 3 | 2 | 2 | 0 | 3 |
| Complements eldercare tools | 2 | 1 | 2 | 0 | 1 |
| Complements mental health tools | 2 | 2 | 1.5 | 0 | 0 |
| **Total**  | **100** | **80** | **70.5** | **39** | **56** |
|  |  |  |  |  |  |

# 3.3 A hybrid system?

So far, the paper has examined each of the four systems on the basis that one or other would be chosen as the appropriate system for Ireland. The other possibility would be to develop either a new system or a hybrid system that would draw on differing strengths of each. For example, the absence of any questions on family support or its sustainability has been identified as a drawback with the SIS. In principle, it could be possible to graft on to the SIS questions around family support modelled on those in either FACE or InterRAI.

Developing an entirely new assessment system is not recommended. There would be a major effort to develop and test such a system, work that could be short-circuited by choosing a system that has already gone through a robust development and testing process, and where there is an array of statistical data from other jurisdictions available as a benchmark.

For needs assessment purposes, the NDA’s research has shown that succinct measures perform as well as more detailed measures in establishing the hierarchy of needs. While adding additional questions to an existing instrument might refine its capacity to generate outcome measures or its value in quality control, such additional questions would generally be redundant in terms of the core function of generating budgets. New variables added to an existing instrument would not be part of any off the shelf formula to translate needs assessment into budgets.

If a hybrid measure was constructed from two or more existing instruments, there is the possibility that licensing costs might be occurred in respect of two or more constituent questionnaires.

The National Disability Authority would therefore advise choosing an existing tried and tested assessment and resource allocation system.

The data to be collected for resource allocation purposes would only be added to if emerging experience in Ireland suggested that additional information would be pertinent to resource decisions.

### An integrated record

However, it may be convenient to integrate the data collected for resource allocation with other data systems. For example, if the chosen assessment tool is missing any item of information routinely collected for the disability databases, it may be convenient to include it on the data form so there is a single integrated record for each service user. However, such additional information would not be part of the scoring algorithm.

# 3.4 Conclusions and recommendations

The National Disability Authority’s advice is that FACE would be the recommended resource allocation system, primarily because

* greater accuracy in matching budgets to needs
* earlier possibility of implementation

Our second preference would be to adopt interRai. This would require additional work to develop a user-friendly and robust cross-disability tool, and associated Resource Utilisation Groups to drive budget assessment.

A procurement process would be required to secure the appropriate licences and software at the best economic price and to configure the system to Irish requirements.

Initial derivation of budgets should be based on an algorithm derived from UK experience, averaging across the local authorities that use FACE. This algorithm should be adapted by adjusting for the differences between Irish and UK pay levels for equivalent staff, effectively converting the UK-based results into equivalent hours of support, and repricing these at relevant Irish wage rates.

The algorithm should be refined over time as data on Irish service users becomes available.

The NDA advises that if FACE is chosen, the order of the items on the questionnaire should be changed, for example to begin with the questions on support needs in relation to activities of daily living, and instrumental activities of daily living, followed by the questions on supports to participate in employment, education, training or other social activities. The more detailed health and medical questions should come at the end.

Some tailoring of supporting materials to the Irish context would be required, e.g. replacing references to the NHS with reference to the HSE.

An implementation team should be put in place to steer the introduction of a common assessment system, alongside an advisory body which involves both service users and service providers. The NDA suggests the introduction of a resource allocation system should begin with people at points of transition – e.g. people leaving congregated settings, school leavers, those leaving rehabilitation training, and people moving into a residential service for the first time.

The NDA is continuing to do research into good practice in implementation, and this will inform further advice in this regard.

The NDA does not see introduction of a resource allocation system as displacing the practice of collecting succinct information via the disability databases. However, to assist in service planning, some additional information on key drivers of resources should be added to the current suite of information collected on the databases, such as complex medical need or the presence of challenging behaviour. The NDA also advises that the two databases, on intellectual disability, and physical and sensory disability, should be amalgamated, and a single database created. This integrated database should also explicitly include people with autism.

# Appendix 1: Comparison of domains and questions in four assessment tools

| **Domain** | **FACE** | **interRAI** | **RAS** | **SIS** |
| --- | --- | --- | --- | --- |
| **Disability** | Disabilities, impairments or health conditions that most affect your independence or daily life |  |  |  |
|  | physical impairment or disability | Documented severity of ID |  |  |
|  | sensory impairment/visual impairment/hearing impairment  | Ability to hear/ Ability to see |  |  |
|  | Emotional well being/mental health/mental health issues/contact with mental health services in the past year/ Other Mental Health issues | Psychiatric diagnosis/contact with psychiatrist  |  | Maintain emotional well being /Maintenance of mental health treatments |
|  | Level of emotional wellbeing – Based on typical week | Mood |  | Emotional well-being |
|  | Worsening psychological condition | Anxiety |  |  |
|  | Contact with Mental Health Services | Contact with formal care providers |  |  |
|  | Routine screening/ Vaccinations | Disease diagnosis |  |  |
| **Health** | General well being  | General health |  | No, some, extensive support needed |
|  | Worsening physical condition | Physical health |  | Exceptional, Medical and Behavioural support needs |
|  |  | Balance |  |  |
|  |  | Gastrointestinal status |  |  |
|  | Recent observation screening, tests or investigations | Service utilization/ Treatments & procedures |  |  |
|  | Breathing independence/breathlessness  | Dyspnea (shortness of breath) |  | Respiratory care(inhalation or oxygen therapy, postural drainage/chest PT/suctioning) |
|  |  | Fatigue |  |  |
|  |  | Extra-pyramidal symptoms (shakes, spasms etc) |  |  |
|  | Falling/recent falls | Falls |  |  |
|  | Pain | Pain |  |  |
|  | Continence | Incontinence |  |  |
|  | Pressure sores/wounds and Other skin conditions | Pressure ulcers and other skin problems |  | Skin care |
|  | Foot Health | Foot problems |  |  |
|  | Currently taking Medication and problems with medication (side effects): details of types/ problems taking medication/using health aids/risk of medicine mismanagement | List of all medications |  | Health risks (severe medical health risks) |
|  | Lapses of consciousness |  |  | Other exceptional medical care |
|  | Oral health | Dental /oral health |  | Tube feeding |
|  | Allergies | Drug allergies |  |  |
|  | Sleep | Sleep problems |  |  |
| **Nutrition** | eating/drinking | How eats and drinks | Eating/drinking | Eating food/ Parenteral feeding |
|  | Diet/ Nutrition  | Chewing problems  |  | Maintain a nutritious diet  |
|  | Swallowing  | Swallowing problems |  | Maintaining Nutritious diet |
|  |  | Mode of Nutritional intake (pureed, tube etc) |  | Oral stimulation or jaw positioning |
|  | Substance use/ smokes | Caffeine, alcohol, tobacco use |  | Substance abuse |
|  | Regular exercise | How many hours of exercise |  |  |
|  | Weight | Nutritional issues (weight loss weight gain |  |  |
| **Behaviour supports needed** | Behaviour affecting self and others/harm to relationships/isolation | Harm to self and others |  | No, some, extensive support needed |
|  |  | Mood and behaviour |  | Emotional outbursts or tantrums |
|  | Harm to self/risk of harm from self-neglect | Self-injurious behaviour | Risk to self | Severe risk or injury to self /Self-directed destructiveness |
|  | Harm of injury to carers/harm to others | Violence | Risk to others | Externally directed destructiveness |
|  |  | Property destruction |  |  |
|  |  | Verbally abusive |  | Severe community safety risk |
|  |  | Physically abusive |  | Assaults or injury to others |
|  |  | Resists care |  |  |
|  |  | Pica |  | Pica |
|  |  | Rumination (regurgitating and re-swallowing food) |  |  |
|  |  | Polydispia (excessively drinking liquids) |  |  |
|  |  | Inappropriate public sexual behaviour |  | Sexual (prevention of sexual aggression or non-aggressive inappropriate behaviour) |
|  |  | Wandering |  | Wandering |
|  |  | Socially inappropriate behaviour |  |  |
|  |  | Echolalia or self-talk |  |  |
| **Health and safety activities** | Are you able to respond to emergencies |  | Staying safe and taking risks | Avoiding health and safety hazardsHow to access emergency services |
|  | Concerns about how others treat you/risk of abuse or neglect | Unsettled relationships |  |  Protecting self from exploitation |
|  | 19 risk factors |  |  |  |
| **Personal care** | Washing whole body | Bathing | Requires support for meeting personal care needs  | Bathing, taking care of personal hygiene & grooming |
|  | Maintaining personal appearance | Personal Hygiene |  |  |
|  | Dressing/undressing | Dressing upper body/ Dressing lower body |  | Dressing |
|  | Undressing |  |  |  |
|  | Using the toilet/managing continence | Toileting, continence, ostomy care |  | Toileting |
| **Significant additional support needs**  | support during day/ support currently /Level of support needed during the night |  | Day time support from two people |  |
|  | support during night |  | Night time support |  |
|  | Need help looking after children/ other dependents |  |  |  |
| **Existing informal support**  | support from family, friends or others (nine domains of help listed) | Social supports/ Informal Helper status/living arrangements | Support from friends and family |  |
|  | Stability of supports | Status of supports |  |  |
|  | Risks of loss of support from carer | Plans for future needs |  |  |
|  | Full break needed by main supporting family member/friend |  |  |  |
|  | Arrangements in place if carer is ill |  |  |  |
|  | Paid form support/paid carer |  |  |  |
| **Mobility** | using transport | Transportation (capacity on 8 pt scale) |  | Transportation |
|  |  | Locomotion - method and capacity to move around home |  |  |
|  | moving around the home | Stairs (capacity on 8 pt scale) |  | Ambulating and moving about |
|  | mobility aids |  |  |  |
|  | transfers |  |  |  |
|  | getting out and about |  |  | Accessing public buildings and settings |
| **Self-care - health etc** | taking medication, difficulty | Medication adherence |  | Taking medications |
|  | Difficulty obtaining access to medication |  |  | Obtaining health care services |
|  | Difficulty self-managing medication |  |  | Learning how to access emergency services |
|  | Difficulty taking medication as prescribed |  |  | Maintaining physical health and fitness |
|  | Staying occupied |  |  |  |
|  | keeping appointments |  |  | Public services in the community |
| **Household tasks** |  | Capacity and performance - 8pt scale | Needs help in the practical aspects of daily living | Needs help with household tasks |
|  | preparing main meal/ preparing drinks/snacks | Cooking |  | Preparing food |
|  | housework | Housework (inc laundry) |  | Housekeeping |
|  |  |  |  | Operating household appliances |
|  |  |  |  | Clothes and Laundering |
| **Shopping and money** | household shopping | Shopping |  | Shopping and purchasing goods and services |
|  | manage own finances | Finances |  | Managing money and personal finances |
|  | Financial difficulties |  |  |  |
|  | Benefits receiving/difficulty in obtaining |  |  |  |
|  | Financial abuse risk |  |  |  |
| **Communication** | using the phone | Phone use |  |  |
|  |  | Making self understood |  |  |
|  | Level of communication/ Communication methods | Capacity to communicate information | Requires support to make views known | Communicating with others about personal needs |
|  |  | Capacity to understand others |  | Using appropriate social skills |
|  | communication | Communication method |  |  |
| **Making decisions** | planning and decision making | Daily decision-making | Requires support to make decisions | Making choices and decisions |
|  |  | Cognitive skills for decision making |  | Advocating for self |
|  | Lack of awareness of hazards | Legal guardian |  | Exercising legal responsibilities |
|  | Currently receiving support for life planning management | Memory/recall ability |  | Obtaining legal services |
|  |  |  |  | Advocating for others |
|  |  |  |  | Belong to and participating in self-advocacy/support organizations  |
|  | memory and orientation | Memory |  |  |
|  |  | Disordered thinking |  |  |
|  |  | Change in mental functioning |  |  |
| **Community living activities** | Social participation and inclusion |  | Accessing community services (shops or library etc) | Participating in recreation/leisure in community settings |
|  | Needs in regards social activities and relationships |  | Engaging with neighbours | Visiting friends and family |
|  |  | Sense of involvement | Participating in community groups | Community activities (church, voluntary groups) |
|  |  |  |  | Interacting with community members |
|  |  |  |  | Socialising within / outside household |
|  |  |  | Being with friends | Making and keeping friends |
|  | Social activities and relationships | Sexual activity | Relationships and social inclusion | Engaging in loving and intimate relationships |
|  |  | Structured activity (formal education, day programme, volunteering) |  | Engaging in volunteer work |
|  |  | Number of days participating in preferred leisure programme |  |  |
| **Employment/learning** | Work/ education/ training | Employment status |  | Participating in training/education decisions  |
|  |  |  | Requires support for participation in Work, learning & leisure | Learning and using job skills |
|  |  |  |  | Completing work-related tasks with acceptable quality |
|  |  |  |  | Accessing job accommodations |
|  |  | Employment arrangements (competitive or supported employment) |  |  Seeking information or assistance form employer |
|  |  |  |  | Changing job assignment |
|  |  |  |  | Completing work tasks to standard |
|  |  | Performance and capacity to work (rated on 8 point scale) |  | Interacting with co-workers / supervisors |
|  |  |  |  |  Interacting with others in learning environments |
|  |  |  |  | Learning and using problem solving |
|  |  |  |  | Using technology for learning |
|  |  |  |  | Accessing training settings |
|  |  |  |  |  Learning functional skills |
|  |  |  |  | Learning physical and health education skills |
|  |  |  |  | Learning self-determination skills |
|  |  |  |  | Learning self-management strategies |
| **Housing need**  | working smoke alarm  |  Accessibility |  |  |
|  | comfortable temperature | Inadequate heating or cooling |  |  |
|  | Suitable and safe | Lack of personal safety |  |  |
|  | Housing situation satisfactory | State of disrepair/squalid |  |  |
|  | Adapted to meet needs | Limited access to home or rooms in home |  |  |
|  | ongoing/ anticipated living arrangements | Residential status/ history |  |  |
| **Other** | telecare |  |  |  |
|  | "are there any areas where risk taking may be positive or beneficial" |  |  |  |
|  | next steps |  |  |  |
|  | How you would like you situation to improve |  |  |  |
|  | Personal background |  |  |  |
|  | Recent events or changes  | Major life stressors/ Stress and Trauma |  |  |
|  | Day-to-day activities and relationships you value the most |  |  |  |
|  | Main current concerns or difficulties |  |  |  |
|  | Staying comfortable |  |  |  |
|  | Reading level/ability |  |  |  |
|  | Risk of loss of autonomy, choice, control |  |  |  |
|  | Risk of loss of daily activities/routines |  |  |  |
|  | Family, carers, advocates view of situation and what would improve it |  |  |  |
|  |  | Several abuse variables |  |  |
|  |  | Strengths  |  |  |

# Appendix 2: Reliability and Validity

Without consistent reliable and valid measurements, one cannot be confident about the results generated by the tools. There are different ways to test whether a tool is reliable. The three most relevant measures of reliability are:

* Inter-rater reliability is the extent to which two or more individuals agree in their assessments. Do different raters give consistent estimates of the same phenomenon?
* Test-retest reliability is the extent the tool gives stable scores over time (presuming nothing has changed)
* Internal consistency reliability is the extent the tools are consistent across items that would expected to be consistent within a test

Validity is concerned with the study's success at measuring what the tool set out to measure.

* Construct validity seeks agreement between a theoretical concept and a specific measuring device or procedure
* Instrumental validity is used to show the accuracy of a measure or procedure by comparing it with another measure or procedure which has been demonstrated to be valid
* Content validity is based on the extent to which a measurement reflects the specific intended domain of content

The final report looking at the implementation of the four tools (NDA 2014) concluded that all four tools were correlated and measured the same thing. Therefore all four could be said to be valid.

Several tools have extensive testing on some instruments but not others, nor the same amount of testing on domains within tools. So, for instance, interRAI eldercare instrument has extensive testing, less so for its other instruments. SIS is well tested for people with an intellectual disability. A further problem is that the interRAI instrument for all people with a disability is not yet completed (the instrument tested by the NDA was a prototype that needs adjusting). Consequently, it is impossible to compare the four tools on a like-for-like basis with complete certainty.

A separate problem is the testers do not use the same statistic to test reliability. Cohen’s Kappa is a measure used to examine inter-rater reliability. Kappa takes account of agreement based on pure chance so is a more rigorous measure than just the correlation between scores. Weighted Kappa calculates agreement where there is more than one level in the answer and gives higher weights to those answers further away from each other. While there is no definitive agreement on the acceptable levels of Kappa but the following rules of thumb are often used:

* < 0 Less than chance agreement
* 0.01–0.20 Slight agreement
* 0.21– 0.40 Fair agreement
* 0.41–0.60 Moderate agreement
* 0.61–0.80 Substantial agreement
* 0.81–0.99 Almost perfect agreement

Cronbach's alpha is a measure of internal consistency, that is, how closely related a set of items are as a group. A high value of Cronbach’s alpha is often used as evidence that the items measure an underlying (or latent) construct. Therefore it is a very useful measure to check that all the items within a tool are measuring the same thing. If Cronbachs’s alpha is used for inter-rater reliability it is checking that the raters’ answers are correlated but not necessarily whether they are the same size.

## FACE

A summary of research on psychometric properties of the FACE mental health tool is available from the FACE organisation, and includes development work funded by and reported to the UK Department of Health, but little by way of peer-reviewed studies. [[56]](#footnote-56) This work showed FACE has good reliability, validity and internal consistency.

## InterRAI

Certain of the interRAI instruments[[57]](#footnote-57) have been well tested. Others instruments, because they are newer, are less well tested. A 12-country study that looked at several instruments found that[[58]](#footnote-58)

* the long term care facilities instrument had a Kappa of 0.75
* home care instrument had a Kappa of 0.69

with other instruments lying between these Kappa scores. Within each instrument, there were lower levels of agreement for some items. There were lower values of Kappa for vision, hearing, nutrition, delirium, some mood items, skin conditions, health instability, dental health, hospital use and social contacts. Nevertheless most of these had moderate to substantial agreement and varied between 0.6 and 0.7 for the Kappa values. The authors quote less agreement for some of the delirium questions but there is not a full listing of all questions.

Guthrie et al (2011) using the interRAI community health schedule for people who are deafblind found that almost 50% of items had a Kappa value of at least 0.60, indicating fair to substantial agreement for these items.[[59]](#footnote-59) Several items related to psychosocial well-being, mood, and sense of involvement had Kappa scores of less than 0.40. Items related to psychosocial well-being and mood had the lowest level of agreement. For the psychosocial well-being domain, two items, ‘fearful of a family member’ (**= 0.09) and ‘other interaction with long-standing social or family member’ (**= 0.08), were considered to have slight agreement. The other items in this domain have slight to substantial agreement. For the mood domain, three items, ‘repetitive health complaints’ (** = 0.06), ‘made negative statements’ (** = 0.04), and ‘repetitive anxious complaints/concerns’ (** = 0.16), were considered to have slight agreement.

The authors conclude that domains that involve more abstract concepts such as mood or comfort with social interaction, are more difficult to assess reliably. This is especially true among individuals with cognitive impairment.

Summarising the research on interRAI for long-term care Sutherland et al (2013)[[60]](#footnote-60) said:

“Most of the published research that evaluates the RAI-MDS[[61]](#footnote-61) 2.0 has been conducted by the group that originally developed the tool and now forms the membership of the interRAI group. Although the RAI-MDS 2.0 has overall good validity and reliability, it is better in some domains than others. …For example, the ADL scale is highly reliable (0.92) but the pain scale is of adequate reliability, bordering on unreliable (0.46) ….. Several studies have documented the unreliability and variable validity of the pain measures in the RAI-MDS 2.0 and noted that it underestimates pain for residents with cognitive impairments…

“Owing to these challenges [unclear clinical guidelines], the RAI-MDS 2.0’s largest weakness is its poor measurement of indicators of mood and behavioral problems, particularly delirium or dementia; which holds true in the US and internationally …the RAI-MDS 2.0 is also weak at identifying depression in older nursing home residents. …

“Under-reporting of behavioral problems, visual acuity and incontinence has also been demonstrated in regards to the RAI-MDS 2.0. Behavioral items in general on the RAI-MDS 2.0 range from low to moderate validity (0.24 to 0.5).…” p12.

In summary, interRAI is well tested (but much of this has been by people affiliated to the interRAI organisation). Much of the testing has been on long-term eldercare and that tool has good validity and reliability. Within the long-term care instrument, some questions have less reliability and validity: mental health status and behavioural problems have been highlighted. Other instruments in the interRAI stable are newer and have less testing but the testing that is there shows good reliability and validity. Individual variables on other instruments demonstrate poorer levels of reliability and validity. Particularly problematic are the variables for mental health and behavioural issues.

## RAS 5

The NDA could find no published psychometric testing for RAS 5.

## SIS

There are extensive published peer-reviewed evaluations of SIS reliability published. Like the interRAI instrument most of this research is by individuals closely associated with SIS. SIS also does not use Kappa as the measurement of inter-rater reliability but an alternative measure of called Cronbach’s alpha which is a measure of consistency between raters (however, the Spanish version testing did report Kappa and this showed substantial agreement).[[62]](#footnote-62)

SIS is designed to understand and analyse the service needs of persons with intellectual disabilities. Its use for people with intellectual disabilities comes with a considerable psychometric testing. SIS is standardised using the results 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.,[[63]](#footnote-63),[[64]](#footnote-64),[[65]](#footnote-65)

Testing of SIS on people who do not have ID shows good reliability. However, it also highlights that the six domains relevant for people ID might not be all relevant for other people with a disability. Rather a shortened version of SIS with four domains had good results for reliability; construct validity and criterion validity (Bossaert et al, 2009).[[66]](#footnote-66) Smith and Fortune record initial inter-rater reliability issues with SIS, and that good inter-rater reliability can be achieved through intensive training and by employing experienced examiners. [[67]](#footnote-67)

As mentioned above, it is not possible to compare all tools as different tools have been tested to different extents on different domains sometimes using different statistics. Indeed, there is a danger of identifying a tool as poor simply because it has the most testing or assuming a tool is poor because it has had little testing. Whatever tool is chosen it would be good for Ireland to undertake such testing.

# Appendix 3: Scores using HSE eldercare weightings

This table presents the NDA’s assessment of how well the different systems would score under the criteria and weightings used by the HSE to choose the single assessment system for older people. The weightings which are given in the first column are out of a total of 100. The scores are from the NDA, the weightings are the HSE’s. The results of this exercise show that interRAI comes marginally ahead of FACE, followed by SIS and finally RAS 5.

In the table ‘people with a disability’ has been substituted for ‘older people’ in the relevant criteria.

|  | **Weight** | **FACE** | **interRAI** | **RAS 5** | **SIS** |
| --- | --- | --- | --- | --- | --- |
| Has good validity (detects what it is supposed to measure).  | 5 | 5 | 5 | 5 | 5 |
| Has good sensitivity (detects most cases of need).  | 5 | 5 | 5 | 5 | 5 |
| Has good ‘inter-rater’ reliability – gives the same results whoever uses it.  | 5 | 4 | 4 | 2 | 4 |
| Has been systematically standardised and developed, including testing.  | 5 | 4 | 5 | 0 | 5 |
| Is sufficiently comprehensive to cover the key domains relevant for the care of older people.  | 4 | 4 | 4 | 2 | 4 |
| The suite of tools includes an structured assessment of the carer(s).  | 4 | 4 | 4 | 4 | 0 |
| The tool takes fair account of age, gender, race, disability, sexuality, and other factors that may have a bearing on needs and care plans.  | 1 | 0.5 | 0.5 | 0.5 | 0.5 |
| The tool should be able to use national standard data-sets where appropriate as they are, and become, available.  | 1 | 0.5 | 0.5 | 0.5 | 0.5 |
| The tool supports international comparability.  | 5 | 5 | 5 | 2.5 | 5 |
| Provides information collections that can be used for care planning and monitoring at the client level, as well as for managerial and national purposes, thus avoiding different, parallel data  | 4 | 4 | 4 | 1 | 4 |
| The tool should produce information that will facilitate transparent decision-making about resource allocation. | 5 | 5 | 5 | 2 | 5 |
| The tool provides status and outcomes measures.  | 5 | 4 | 4.5 | 1 | 2.5 |
| Highlights needs and risks and triggers actions / follow-up.  | 1 | 0.8 | 1 | 0 | 0.3 |
| Identifies a person with a disabilty’s preferences, needs, and associated risks.  | 2 | 1.3 | 1.3 | 0 | 2 |
| The tool should identify people with a disability’s views, wishes, strengths and abilities.  | 2 | 1.3 | 1.3 | 0 | 2 |
| The tool should make the impact of people with a disability’s environments, relationships and other factors on their needs explicit.  | 2 | 2 | 1 | 1 | 2 |
| Allows for easy comments on the form in use.  | 1 | 1 | 0 | 0 | 1 |
| Provides evidence for MDT recommendations based on care needs and preferences.  | 2 | 1 | 1 | 1 | 1 |
| Enables adaptations for different cultural and ethnic groups.  | 1 | 1 | 1 | 1 | 1 |
| Is practical to administer.  | 2 | 2 | 1 | 2 | 1 |
| The suite of tools provides a good match to our process of assessment in all settings where older persons are assessed i.e. – at home, in the community, in acute hospitals, or in any designated centre for people with a disability.  | 2 | 2 | 2 | 2 | 2 |
| The tool helps professionals to link different parts of the assessment, and to evaluate risks, and to aid referral to other agencies. | 2 | 1.5 | 2 | 0 | 0.7 |
| The tool is suitable for use by a range health and social care professionals.  | 2 | 2 | 2 | 2 | 1 |
| The tool satisfies statutory requirements with respect to confidentiality. AND the tool satisfies statutory requirements with respect to consent.  | 1 | 1 | 0 | 0 | 1 |
| The wording and structure of the tool facilitates a person-centred conversation with the person with a disability, AND The wording and structure of the tool facilitates an assessment conversation suitable for the professionals.  | 1 | 1 | 0 | 0 | 1 |
| Manuals and guidance exist and give clear instructions on how the tool should be used, by whom and when.  | 2 | 1 | 1 | 0 | 1 |
| The Introductory Training should provide sufficiently clarity to enable effective use of the tool.  | 2 | 2 | 1 | 1 | 1 |
| The training is not too overly time-consuming.  | 2 | 2 | 1 | 2 | 1 |
| The tool is supported by a financially sustainable research and development process | 2 | 2 | 2 | 2 | 2 |
| The tool should not be contractually bound to the provider of a single software solution.  | 2 | 0 | 1 | 2 | 0 |
| Ultimate cost[[68]](#footnote-68) | 20 | 14.5 | 20 | 20 | 12 |
| **Total** | **100** | **84.4** | **86.1** | **61.5** | **73.5** |

# Appendix 4 – systems to derive cost formulas

## Costing systems associated with each tool

Each resource allocation system has developed its own mechanism for converting rankings into resources. This Appendix sets out the mechanisms associated with each of the four systems studied, along with information from site visits to a number of English local authorities

### FACE

FACE has a built-in algorithm to convert the information collected on the individual’s profile to a cost figure. The system was developed originally in partnership with Manchester University and further refined by the FACE organisation. The algorithm which has been developed is a complex one, but fundamentally the method used identifies hours of support need associated with different elements of the individual’s profile – whether they need help with dressing, feeding, communication etc. It is based on a series of logical rules (if this, then that), which has an in-built mechanism to eliminate double-counting. For example if someone needs an individual to help them get out of bed, and an individual to be available at all times due to behaviour issues, that can be the same support person for both tasks. The algorithm is embedded in an Excel spreadsheet and converts the information on the individual’s profile into a corresponding resource figure. The system has been continuously refined to provide a high degree of accuracy in matching predicted costs and costs of actually delivering a service.

### InterRAI

The underlying principle of the interRAI cost formula is to take the profile information on a sample of service users, including their current hours of support, and to develop a series of clusters who are expected to require similar levels of resources. These are called Resource Utilisation Groups or RUGs. The method used is a combination of statistical clustering techniques plus the potential to add in logical rules. For example in the recent test to develop costing for their ID instrument, there were 30 clusters identified. For nursing home care, InterRai’s RUG-III has 44 clusters, and RUG-IV has 66 clusters. These clusters include people with exceptionally high costs, so no outliers are outside the system.

### RAS 5

In Control, the organisation that developed the RAS 5 system, has a recommended method to derive a link between RAS 5 scores and financial allocations, or a ‘pounds for points’ method.[[69]](#footnote-69)A desktop exercise produces a sample of scores from a group of individuals along with the cost of their current support. The data is inputted to a spreadsheet. Scores are ranked from high to low, and these are set against current costs in a scale from high to low. Scores in each percentile bracket are aligned with the corresponding percentiles of spend, i.e. the person with the highest score is set against the highest spend and so on down the table to the person with the lowest score attracting the lowest spend.

The next step is to use these initial results based on current practice to begin to construct an allocation table. A contingency amount is set aside to allow for cases where the budget allocation may prove inadequate, or where circumstances may change for an individual. Then patterns are looked for in the data – people with similar support needs should be allocated similar amounts of funding – that may enable a ‘skeleton’ allocation table to be constructed. The monetary amount of each price point is based on locally-determined cost levels. The allocation table may be built in funding ‘bands’ where scores and funding are averaged across a group. For example, the funding spent on the top 10% of service users by cost of their services would be matched to the top 10% of points scored, to create a relationship between budget and scores. Alternatively, instead of banding, individual price points may be matched to individual points scored. This generates a formula or allocation table. Any new applicant will have their points calculated, and their indicative budget will be based on their total points, multiplied by the ‘pounds for points’ formula at the particular points level.

The scores in the RAS 5 system are additive. So a person who needs constant supervision, for example because of challenging behaviour or dementia, and also needs help with tasks of daily living such as getting dressed would get points for both elements. When translated into a budget, this means that there would be additional budget awarded to cover help with getting dressed, even though this task could be performed by the person who is there to offer supervision.

### Supports Intensity Scale

The Supports Intensity Scale (SIS) raw scores are converted into standardised scores which reflect the percentages of a large intellectual disability population who achieved different levels of raw scores. But these ‘normalised’ scores cannot in themselves be used to generate cost estimates for support needs. SIS is not sufficient in itself to derive cost estimates, as it does not count what degree of family or informal support is available.

The method used is as follows:

* Select a sample of service users
* Administer the SIS questionnaire
* Administer supplementary questionnaires as appropriate (e.g. Oregon questions which ask about complex behaviour issues or criminal history)
* Run a series of regressions using
* the replies to individual questions on the SIS form, and combinations of these
* data from any supplementary questionnaires
* data on issues such as type of residential setting, natural community supports, and state-wide income per head
* Select the regression with the best fit. The SIS variable used may not be the total score, but could be the score from a particular combination of answers. Typically the SIS score alone will contribute 30% towards the variation – the individual’s living arrangements and access to informal supports (e.g. from family members) are also considerable drivers of expenditure
* The coefficients of the ‘best fit’ regression equation are then applied to other service users to generate their expenditure level
* Service users may be grouped in a number of broad expenditure brackets, or assigned a more tailored budget

New service users are assigned budgets which are determined by this calculated formula. So the first costing formula is rooted in the costs of delivering traditional services in the traditional way. As a process of individualised budgeting is rolled out, further information is collected on SIS scores and on actual costs of services in the individualised funding model. After an interval, the model is recalculated.

The team which has developed most of the resource allocation systems based on SIS suggests that about 7% of those with exceptionally high costs should be costed individually outside of the resource allocation system, and that a reserve budget be held for that purpose. [[70]](#footnote-70)

## Learning from study visits to 3 English local authorities

The National Disability Authority visited three local authorities in England to find out, among other matters, how they had derived their cost formula to link resource allocation to the points in a RAS-type scheme. Resource allocation schemes are used to derive personal budgets for people to purchase their own care support.

### Two-stage process – indicative and final budgets

In England the system for personal budgets is that an individual assessment is used to estimate personal budgets. Assessments are done independently by local authority social workers. The points scored on a RAS assessment are translated into indicative budgets through the local formula used. The recommendation from the Association of Directors of Adult Social Services is that up to 25% of the budget is held in reserve to ensure there is funding available for situations where the indicative budget would undershoot the person’s need, including people whose exceptional needs are not adequately captured by the RAS formula.

The second stage is to discuss with the individual what the plan would be to meet their care needs, given the indicative budget. This stage may result in a final budget which is higher or lower than the indicative budget.

The NDA visited three local authorities in England, out of a list suggested by the In Control organisation, to learn more about how they derived their resource allocation formulas for indicative budgets, as well as other aspects of the systems for introducing and administering personal budgets. A summary of how these three authorities derived their formulas for converting RAS scores to cash is below.

### Cambridgeshire

In Cambridgeshire, services are generally commissioned out, and most providers are from the private sector. The starting point was therefore a very good understanding of what current services are costing.

Two people devised the ‘points for pounds’ schedule – a senior person with a finance and social care background, and an experienced social care practitioner. They started with a desk exercise on a sample of 300 service users, excluding outliers who would cost substantially more or substantially less than the norm. They modelled the kind of care people were getting, e.g day care, supported living in group homes of different sizes, and calculated the average costs of such care. From this, clients were assigned to one of five different bands, based on what they were currently costing, minus 25%. The upper limit was the benchmark cost of residential care. Where individual service providers were charging more than the going rate, the presumed cost was adjusted downwards to the going rate.

Questionnaires, based on RAS 3 from In Control, were completed for the 300 service users. Using their judgement, the two senior staff equated scores on the questionnaire, first with the bands and then with individual cash amounts within these bands, to develop a ‘pounds for points’ scale. There was not a direct linear relationship between points and pounds. Those in the higher points brackets received a higher weighting for their points.

Indicative amounts are based on the individual’s bands for their points, plus an addition where high support was indicated, e.g. where someone needed two staff on for some of the time, or where a waking overnight would be needed. The initial indicative amount is normally around a mid-point of a funding band. For example, someone on 25 points would be offered an initial indicative amount of £17,713, but this could increase up to the top of the relevant band - £25,000.

Where there are complex needs, the council will check whether there are any exceptional care needs. This could arise where there is challenging behaviour; complex physical needs; or complicated health needs (peg feeding, epilepsy). Examples of extra care needs, which attract a bonus on the ‘points for pounds’ system, are 2 to 1 support, or a waking night. Some older people , or those with physical disabilities, will occasionally need two people for lifting. People with Acquired Brain Injury sometimes have additional needs over other groups.

The requirement for extra care needs is checked automatically for those who come out in the highest points bracket. While the maximum is normally £61,000, it can go up to £100,000 if there are these extra needs. Waking night cover is costed at £38,000, divided by the number of persons in the group home (5-person group home - £7,600). If someone needs 2:1 care, their care points are doubled. Sleep-in care – attracts an extra allocation of £15,000. Where there are specialist care providers (e.g. those who support people with intellectual disability with such challenging behaviour as a history of sex offence) the hourly rate offered is £4 more than the standard hourly rate.

### Hartlepool

Hartlepool Council did a desktop exercise with 300 cases, and looked at their current funding. As all services were commissioned, they had good cost information. Individuals with very low or very high costs were taken out – this may skew the picture. They held back 15% of the budget as a cushion. These 300 cases were awarded points – the Hartlepool points system is based on RAS 5 but has been calibrated to produce a maximum of 100 points.

They tracked the percentage of budget against percentage distribution of points. They calculated a cash value for every point, and then smoothed it to provide ranges of pounds for points. They took the list of service users in groups of five, averaged the sums of money involved for each group of five, then rounded it up or down to the nearest £10 a week.

Hartlepool Council calculated different £ for points schemes for people with intellectual disability, and for those with a physical disability. For people with intellectual disability, the top allocation band, for those with 91+ points, is £35,000 a year, where for someone with a physical disability the top allocation band, for those with 91+ points, is £17,650.

In a peer-reviewed journal article, Slasberg et al. have shown that Hartlepool’s resource allocation system has produced a wide dispersion between the ‘indicative’ budgets produced by the formula, and the actual personal budget agreed based on detailed personal service planning, with the average difference between indicative and actual budgets varying by a factor of 3.84. [[71]](#footnote-71)

### Solihull

This Council used the RAS 4 tool developed by In Control. To find a formula to convert scores to cash, the Council first did a desktop exercise with 100 case files. They applied RAS 4 to these case files using an initial points schema, and looking at what was currently spent on those 100 people. They divided the total spent on the 100 people by the total number of points to get a price per point, then applied the 25% deflator which was the national instruction.

Issues identified by the council with this approach

* The sample of 100 was too small
* It is not always easy to know what individuals are already costing – it is important to factor in overheads, and to fully-cost internally-provided services
* They looked at current costs, not future costs or affordability
* It was based on the current care model
* It built-in existing inequities between clients
* It is difficult to be sure that the indicative allocations emerging will be affordable and sustainable
* The system does not generate indicative budgets for people with physical or intellectual disability that are close to the final person budget
* There is no built-in system to deal with outliers, people with unusually heavy support needs, which end up going to appeal
* On reflection, they introduced the system too quickly, they needed more development time

# Appendix 5 – FACE server requirements

The following specification is required to run the FACE analysis software

## Server software requirements

* Windows Server 2008 R2 or Windows Server 2012 R2
* SQL Server 2008 R2 or SQL Server 2012 R2 or SQL Server 2014
* .NET Framework 4.5.2
* IIS 7 or 8

## Server hardware requirements

* Web Server
* Quad core CPU x64 2GHz or faster
* Minimum 8GB ECC RAM (16GB or more recommended)
* HDD or SSD storage

## Database Server

* Quad core CPU x64 2GHz or faster
* Minimum 8GB ECC RAM (16GB or more recommended)
* Local SSD storage recommended

Minimum of local HDD or low-latency SAN

* Estimated storage requirement of 1GB per 500 service users, per year for intensive use

### Virtualised Server Strategy

* If using virtualised servers, it is recommend to use two virtual machines with one as the web server and one as the database server.
* Use the same minimum specification as Dual Server above.

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# Glossary

|  |  |
| --- | --- |
| AAIDD | American Association for Intellectual and Developmental Disabilities |
| FACE | Functional Analysis of Care Environments |
| HRB | Health Research Board |
| NDA | National Disability Authority |
| NIDD | National Intellectual Disability Database |
| NPSDD | National Physical and Sensory Disability Database |
| RAS 5 | Resource Allocation System from In Control, Version 5 |
| SIS | Supports Intensity Scale |

1. It is recognised that people may acquire disabling conditions in their older years, which can be ameliorated by access to recognised specialist disability rehabilitation and support services geared to particular impairments [↑](#footnote-ref-1)
2. NDA (2011) The Introduction of Individual Budgets as a Resource Allocation System for Disability Services in Ireland: A Discussion Paper. www.nda.ie/Policy-and-research/Research/Research-publications/The-Introduction-of-Individual-Budgets/ [↑](#footnote-ref-2)
3. SQW (2013) National Disability Authority Resource Allocation Feasibility Study. http://nda.ie/ndasitefiles/NDA\_Resouce\_Allocation\_Feasibility\_Study\_Jan2013.pdf [↑](#footnote-ref-3)
4. NDA (2014) National Disability Authority Resource Allocation Feasibility Study phase 2. [↑](#footnote-ref-4)
5. In 2013 there were 28,000 people registered on the National Intellectual Disability Database. The National Physical and Sensory Disability Database has not achieved full coverage of its original target population, estimated at 10.53% of the population aged below 66, which, would translate into about 43,000 potential registrants for 2014 (the number of potential registrants identified by HSE and service providers was considerably lower – 34,000). Together these would sum to 71,000. About a third of these are children. [↑](#footnote-ref-5)
6. HSE (2012) Single Assessment Tool for Older Persons in Ireland - Final Report of the Working Group [↑](#footnote-ref-6)
7. NDA (2014) National Disability Authority Resource Allocation Feasibility Study phase 2 [↑](#footnote-ref-7)
8. Some organisations provide a mixture of continuous support services such as personal assistants that are readily modelled using a resource allocation tool, alongside advice and information services and brief transition support, that is not readily captured by such systems. [↑](#footnote-ref-8)
9. The financial data in the Value for Money and Policy Review of Disability Services does not allow an easy breakdown to be made between expenditure on disability support services, on therapy services, and on assistive technology/aids and appliances. [↑](#footnote-ref-9)
10. A 24/7 residential service could entail up to 168 hours of support a week, whereas a full week’s conventional day support might entail 35 hours of support services. [↑](#footnote-ref-10)
11. No help from family or friends = 1; only some of the help I need = 0.7; most of the help = 0.5; nearly all the help = 0.3 [↑](#footnote-ref-11)
12. While in principle a link between individual assessment profiles and costs could be constructed using the ‘basket of services’ method, it would not be feasible to use statistical techniques to derive a formula to link assessment profiles and corresponding costs. This is because there is no robust comparable cost data across different services. Disability services in Ireland are delivered by a large number of different organisations with different service models, and each with its own accounting system, accounting terminology. The Value for Money and Policy Review of Disability Services found it a challenging task to attempt to derive comparable cost data. [↑](#footnote-ref-12)
13. Severance and Campbell (2008). What is a funding formula? AAIDD White Paper [↑](#footnote-ref-13)
14. Van Loon (2008) The Arduin Benchmark – a method of resource allocation on the base of the Supports Intensity Scale. AAIDD White Paper [↑](#footnote-ref-14)
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16. NDA has examined the raw data from this study and is satisfied that there is a very high convergence of values after the correction process. Prior to these adjustments, the correlation reached was 74%. [↑](#footnote-ref-16)
17. Slasberg and Beresford (2014) Response to the paper ‘Modelling the relationship between needs and costs: how accurate resource allocation can deliver personal budgets and personalisation’, Research Policy and Planning 30(3) 193-196. A personal communication from FACE in November 2013 cited results by care group averaged over the last 28 FACE resource allocation systems established in different councils. The cited results were average correlations between predicted and actual cost that ranged between 0.985 and 0.994 across different care groups. [↑](#footnote-ref-17)
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19. Martin, Fries, Hirdes and James (2011). Using the RUG III classification system for understanding the resource intensity of persons with intellectual disability residing in nursing homes. Journal of Intellectual Disabilities 15(2) 131-141 [↑](#footnote-ref-19)
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25. Kimmich et al (2009) op. cit, Appendix B, p. 7-8 [↑](#footnote-ref-25)
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30. Personal communication [↑](#footnote-ref-30)
31. http://aspe.hhs.gov/daltcp/reports/2011/StratEng-B.htm [↑](#footnote-ref-31)
32. [http://aspe.hhs.gov/daltcp/reports/2011/StratEng-B.htm - note82](http://aspe.hhs.gov/daltcp/reports/2011/StratEng-B.htm#note82) [↑](#footnote-ref-32)
33. for instance Miller et al (2013). Understanding the RAS. In Control <http://www.in-control.org.uk/media/137728/understanding_the_ras.pdf> [↑](#footnote-ref-33)
34. Department of Health (2012) Future Health: A Strategic Framework for Reform of the Health Service 2012-2015. Dublin [↑](#footnote-ref-34)
35. This task is among the terms of reference of Working Group 5 (Management & Information Systems) of the Value for Money and Policy Review Implementation Programme. The NDA’s advice is the scale of the task of introducing a resource allocation system requires a separate implementation team [↑](#footnote-ref-35)
36. In some cases, specialist disability services are involved, for example specialist services to support people experiencing onset of sight loss or hearing loss. [↑](#footnote-ref-36)
37. There have been some criticisms that having the same HIQA personnel conducting inspections of nursing homes and of residential disability services has over-focused disability inspections on medical and nursing issues compared with questions of autonomy and participation [↑](#footnote-ref-37)
38. See Appendix 5 [↑](#footnote-ref-38)
39. Van Loon (2008) Aligning Quality of Life Domains and Indicators with SIS data. AIDD White Paper. [↑](#footnote-ref-39)
40. For example Clifford, Padda, Brown, Saunders and Demarche (2012) Investing to save? – assessing the cost-effectiveness of telecare. Nottingham: FACE [↑](#footnote-ref-40)
41. One striking negative health outcome reported in the IDS-Tilda survey, Wave 2 (McCarron et al 2014), was the presence of polypharmacy. Another was that almost 40% of older people with intellectual disabilities suffered from chronic constipation. This aspect of health is recorded in InterRai but not in FACE. [↑](#footnote-ref-41)
42. Tribble and Wrigley (2008) Utilising the Supports Intensity Scale with direct links to individual support planning. AAIDD White Paper. [↑](#footnote-ref-42)
43. The Brothers of Charity Galway services have a sophisticated data system which among other items records incidents of challenging behaviour, and whether these are self-directed, directed at other residents, or at staff. These data are able to identify how such the prevalence of such incidents has responded to service changes, e.g. movement from a congregated setting to the community, and to track improvements in the quality of life of individuals or co-residents where challenging behaviour has reduced. They are also able to identify areas of their service for attention where the number of such incidents are higher than the norm elsewhere. [↑](#footnote-ref-43)
44. The physicist Stephen Hawking is an example of someone who is eminent in his field of employment, at the same time as having very high support needs. [↑](#footnote-ref-44)
45. WHODAS 2 is a World Health Organisation data collection instrument that collects data on difficulty in the following areas – getting dressed; taking a bath/shower; standing for a long period; walking long distances; concentrating on something; learning a new task; household responsibilities; day to day work/school, maintaining a friendship, dealing with strangers, joining in community activities, emotional effect of disability. [↑](#footnote-ref-45)
46. For example, the level of medical detail collected in InterRai e.g. on types of medication, forms of administration and extra-pyramidal symptoms would not be required for aggregate service planning [↑](#footnote-ref-46)
47. The NPSDD in principle excludes people with disabilities who are aged over 66, although people with a disability who were registered prior to reaching age 66 remain on the books. It makes sense to retain people who have a lifelong disability on any single national disability database after they have reached pension age. . [↑](#footnote-ref-47)
48. The domains are Individualised Support and Care (which includes privacy, choice, relationships with family and community); Effective Services (which includes a personal support plan, and the quality and homeliness of the accommodation); Safe Services (which includes freedom from abuse and neglect, and supports to positive behaviour and emotional well-being); Health and Development (which includes supports to good health, and opportunities for education, training and employment); Leadership Governance and management; Use of Resources; Responsive Workforce; and Use of Information [↑](#footnote-ref-48)
49. InterRai argue that while self-assessment by funded units may build in an incentive to upcode, the tracking of negative information for quality assurance purposes provides a counterweight [↑](#footnote-ref-49)
50. Ivey et al (2008) Relating the Supports Intensity Scale information to Individual Service Plans. “The general experience to date is that SIS-related data needs to be combined with other information to link person-centred planning with individual supports planning. This is because SIS, like all standardised, norm-based assessments wherein scores are derived by comparing the individual’s score with the scores of other people with disabilities, does **not** provide information about the person’s desired life experiences and goals.“ American Association on Intellectual and Developmental Disabilities White Paper [↑](#footnote-ref-50)
51. Tribble and Wrigley (2008) Utilising the Supports Intensity Scale with direct links to individual support planning. AAIDD White Paper. [↑](#footnote-ref-51)
52. Interrai in particular collects extremely detailed information on aspects of health status, reflecting its origins as an eldercare assessment. [↑](#footnote-ref-52)
53. NDA (2005) Guidelines on person-centred planning in the provision of services for people with disabilities in Ireland [↑](#footnote-ref-53)
54. Lincoln Centre (2004) [↑](#footnote-ref-54)
55. FACE offered 3 options – a basic package run on Excel, and intermediate and comprehensive packages with specific additional software supplied. The score in the table reflects the cost of the intermediate package. FACE would score 5 if the basic option were chosen, and 2 if the comprehensive option were chosen. [↑](#footnote-ref-55)
56. Clifford (2022) FACE Assessment Tools and Outcome Measures for Mental Health: The Evidence Base. Nottingham: FACE [↑](#footnote-ref-56)
57. interRAI refers to its tools as ‘instruments’. Tools and instruments are used interchangeably in this paper. [↑](#footnote-ref-57)
58. Hirdes et al (2008) http://www.biomedcentral.com/1472-6963/8/277 [↑](#footnote-ref-58)
59. Guthrie et al (2011) http://web.b.ebscohost.com/abstract?direct=true&profile=ehost&scope=site&authtype=crawler&jrnl=07487711&AN=70396972&h=G2OGw33%2f%2f1jLgPb5U3WRrUXqAqnFu5prGNNZHL7tCKdKDxOcqtewxB1DWq0wQwNcI0VJZuW2uw4O%2b9qmPgYP6w%3d%3d&crl=c [↑](#footnote-ref-59)
60. Sutherland, Repin and Crump (2009) http://www.albertahealthservices.ca/Publications/ahs-pub-ltc-pcbf.pdf [↑](#footnote-ref-60)
61. MDS stands for minimum data set and refers to USA mandated data collection. [↑](#footnote-ref-61)
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63. Weiss, J., Lunsky, Y., Tasse, M., & Durbin, J., (2009). Support for the construct validity of the Supports Intensity Scale based on clinician rankings of need. Research in Developmental Disabilities, 30, 933-941. [↑](#footnote-ref-63)
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65. Kuppens, S., Bossaert, G., Buntinx, W., Molleman, Van den Abbeele, A., Maes, B., (2010). Factorial validity of the Supports Intensity Scale (SIS). American Journal on Intellectual and Developmental Disabilities, 115, 4, 327-339. [↑](#footnote-ref-65)
66. Bossaert G, Kuppens S, Buntinx W, Molleman C, Van den Abeele A, Maes B (2009) Usefulness of the Supports Intensity Scale (SIS) for persons with other than intellectual disabilities attp://www.sciencedirect.com/science/article/pii/S0891422209000882 [↑](#footnote-ref-66)
67. Smith G and Fortune J (2006) Assessment Instruments and Community Services Rate Determination: Review and Analysis. Portland, Oregon: HSRI [↑](#footnote-ref-67)
68. FACE offered 3 options – a basic package run on Excel, and intermediate and comprehensive packages with specific additional software supplied. The score in the table reflects the cost of the intermediate package. FACE would score 20 if the basic option were chosen, and 8 if the comprehensive option were chosen [↑](#footnote-ref-68)
69. In Control (2013) Understanding the resource allocation system. http://www.in-control.org.uk/media/131598/understanding\_the\_ras%20-%20final%20for%20print.pdf [↑](#footnote-ref-69)
70. See, for example, Kimmich et al (2009) Developing Individual Budgets and Reimbursement Levels using the Supports Intensity Scale, Appendix B p. 16 [↑](#footnote-ref-70)
71. Slasberg C, Beresford P, Schofield P (2012) ‘How self directed support is failing to deliver personal budgets and personalisation.’ Journal of Research Policy and Planning 29(3), 161-177 [↑](#footnote-ref-71)