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When normal scores don't equate to independence: recalibrating ratings of neurobehavioural disability from the 'St Andrew's – Swansea Neurobehavioural Outcome Scale' (SASNOS) to reflect context-dependant support

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Running Title

Assessment of context-dependent support on NBD

Key Words: Head injury, traumatic brain injury; assessment; neurobehavioural; rehabilitation

When test scores in the normal range don't equate to true independence: a method to convey the impact of context on ratings of neurobehavioural disability and social handicap using the 'St Andrew's – Swansea Neurobehavioural Outcome Scale' (SASNOS).

ABSTRACT

Primary objective

Context is critical to interpretation of measurement instruments that capture acquired brain injury (ABI) outcomes. Ratings reflect behaviours and abilities observed in a particular setting; it cannot be assumed results are generalisable beyond these. This study explored the utility of a method to convey the impact of context-dependant support given on ratings of neurobehavioural disability (NBD) using the St Andrews-Swansea Neurobehavioural Outcome Scale (SASNOS).

Methods and procedures

A supplementary SASNOS scoring system was developed using a mixed-methods approach.

Dependency ratings were used to recalibrate standardised SASNOS scores to reflect support received. To aid interpretation, an expert panel reviewed SASNOS ratings for 50 ABI cases participating in residential neurobehavioural rehabilitation programmes. An end-user survey was undertaken to explore some of its psychometric properties. Finally, a representative case study was employed to illustrate its clinical utility.

Main outcomes

The expert panel identified three dependency profiles: (1) *Normal/Independent*; (2) *Normal/Dependent*, and; (3) *Abnormal/Review*. Survey results supported face and construct validity of the supplementary system; the case study demonstrated benefits of discriminating between dependency profiles.

Conclusions

The supplementary scoring system enables SASNOS to convey the impact of support received on ratings of NBD, solidifying its usefulness for measuring outcomes in rehabilitation.

INTRODUCTION

Neurobehavioural disability (NBD) is the product of interactions between damaged neural systems and neurocognitive impairment, further modified by premorbid personality traits and post-injury learning [1]. It comprises elements of executive and attentional dysfunction, poor insight, problems of awareness and social judgement, labile mood, altered emotional expression, poor impulse control and a range of personality changes that impose serious constraints on psychosocial recovery [2]. Behaviour disorders associated with NBD are enduring [3] and create severe difficulties for families [4, 5]. Furthermore, the presence of NBD has been associated with poor engagement in rehabilitation which has an impact on psychosocial outcome [6, 7, 8]. Fortunately, neurobehavioural rehabilitation (NbR) has demonstrated many behaviour problems can be improved and their psychosocial impact reduced [9].

In order for NbR to successfully target symptoms of NBD, reliable and valid methods of assessing them are required. A range of instruments are available for the measurement of NBD. In a comprehensive review of ABI tests, scales and questionnaires, Tate [10] described in detail the attributes and properties of over twenty instruments concerned with this purpose; previously, Wood, Alderman and Williams [11] also conducted in depth review of eight of the most well-known NBD measures. Instruments comprise either global measures of disability, providing an overview of strengths and needs, usually by means of a questionnaire or multiple rating scales; or focal instruments, often comprising observational recording measures, which enable assessment of specific areas of concern. As well as playing an important role in helping to identify rehabilitation goals, measurement instruments are also used to track response to rehabilitation through repeat assessment; they also inform discharge planning by highlighting unmet needs and also inputs that will continue to be required to maintain levels of autonomy attained within rehabilitation services.

However, a point to consider when interpreting results from measurement instruments is that assessments will be influenced by, and reflect, the context in which they are made. For example, ratings of participants in residential rehabilitation programmes will reflect prevalence of behaviours and functional abilities in that setting and it cannot be guaranteed results have universal validity and will be generalisable to other settings [12]. With regard to NBD, symptoms and behaviours attributable to this are underpinned by a range of factors that are either static and fixed, or dynamic and flexible [13]. In the case of the latter, there is opportunity that new learning means rehabilitation improvements are made that are independent of the rehabilitation environment, which sustain and are generalisable following discharge. Conversely, whilst it is possible to reduce handicap and disability associated with static, fixed variables that drive NBD, improvement will remain dependent on whatever form this support, provided within the rehabilitation environment, takes if it is to prove sustainable in the future. Modifying the environment, either physically or regarding what occurs within it, to reduce NBD is a key component of NbR [14]. The context assessment takes place in is therefore very important in understanding the results arising from assessment instruments as they will not typically incorporate measures that indicate how much support is given to circumvent or ameliorate NBD symptoms, whether this be through encouragement or occasional prompting, modification of the environment, use of technology or purpose designed interventions.

The importance of gauging the extent of support received in interpreting assessment results has been acknowledged for some time. For example, measures have been developed to capture how much input is required to provide support, determined by how many therapy disciplines and hours (including nursing care) an individual requires [15, 16, 17]. However, levels of dependency (measured by these instruments) do not have a consistent relationship with change in measures of behaviour and functional skills and are therefore of guestionable benefit to NbR services [18]. In

addition, whilst interdisciplinary and multidisciplinary teams may be able to precisely quantify how many hours of therapy are provided by individual disciplines, NbR services are typically delivered by transdisciplinary teams, where role-release crosses traditional disciplinary boundaries, undermining the ability to reliably estimate hours of care.

One option to overcome these difficulties is to apply various external criteria to weight ratings and scores to assist interpretation and improve test validity. There are precedents for using such systems to modify outputs from various psychometric instruments in NbR. For example, the 'Overt Aggression Scale – Modified for Neurorehabilitation' (OAS-MNR) [19] is an observational recording measure that enables reliable and valid information concerning four types of aggressive behaviour to be captured: verbal aggression, and physical aggression against objects, self and others. Within each of these types, behavioural observations are further categorised by level of severity using an ordinal scale, ranging from 1-4, equating to mild, moderate, severe and very severe. However, this system creates difficulties when interpreting pooled data. Consider the case of a patient who, in the first week of their rehabilitation, is physically aggressive against other people a total of ten times, each rated as 'severe'. The mean severity of aggression is (total severity/number incidents) 30/10 = 3.0. In the final week of their rehabilitation, the same patient is verbally aggressive ten times, all of which are rated 'severe', resulting in a mean severity score of 30/10 = 3.0. Comparison of these summary statistics without the benefit of any description of context suggests no progress has been made, as both frequency (10) and mean severity (3.0) of aggression are identical. It is therefore only meaningful to compare ratings of severity within a category of behaviour, not between different categories, as they are not equivalent. This is clearly apparent when the definition of severe physical assaults ('attacks others causing mild-moderate physical injury - bruises sprains, welts') is compared to severe verbal aggression ('swearing, moderate threats clearly person directed at others or self'). The different descriptors clearly show the behaviour of the person has changed,

from physically assaultive to verbally aggressive, but this is not reflected in comparisons of mean severity, which are the same.

This example illustrates how a numerical scale can meaningfully classify different levels of the same behaviour, but also result in error if the same scale is used across different categories of behaviour that are not equivalent. To aid interpretation of OAS-MNR data and enable pooling and comparison of ratings of severity of aggression amongst the different categories of aggressive behaviour, Alderman, Knight and Morgan [19] recommended use of a weighting system. They established a hierarchy of severity for the four categories of aggression using judges who placed them in rank order, with a numerical weight from 1-4 assigned to each. Verbal aggression was weighted as '1' (least severe), physical aggression against objects '2', physical aggression against self '3', and physical aggression against other people '4' (most severe). These weights are employed to modify severity ratings for each category, enabling more valid pooling of data and the ability to make meaningful comparisons between the four classes of aggression. To do this, the severity rating of an individual behaviour is transformed by multiplying it by the weighting for that category. In the case of the patient whose recordings were discussed earlier, the mean weighted severity score for the last week spent in rehabilitation is unchanged (applying the category weight of 1 makes no difference). In contrast, multiplying each of the severity ratings of 3 by the rank pertaining to the category of 'physical aggression against other people' (4) results in a weighted severity score of 12 for each of the ten incidents recorded. As all behaviours were rated 'severe', a mean weighted severity score for the first week spent in rehabilitation (120/10) of 12.0 is calculated. The point is that whilst the frequency of aggression was identical for both periods, weighting severity to reflect important qualitative differences between categories of behaviour results in two scores that now clearly indicate positive outcome (12 vs. 1).

Another example of a weighting system being applied to increase discriminant and predictive validity is the Multiple Errands Test - Simplified Version (MET-SV) [20]. The MET-SV is a test of executive function carried out within a shopping centre where participants are required to carry out a range of everyday tasks whilst planning to ensure a number of rules are not broken. The test is scored using a number of criteria, including number of rule breaks and number of task failures. Alderman and colleagues found that MET-SV error scores were able to discriminate successfully between neurologically healthy controls and people with ABI (44%), but observed notable qualitative differences in the errors made across the groups. For example, whilst 25 errors were evident across both groups, a small number (4) were only observed in controls whilst 33 were characteristic of ABI participants. Alderman and colleagues argued this information should be considered when scoring the test. Consequently, they incorporated a weighted scoring system based on the performance of neurologically healthy controls: errors were scored '1' if they had been demonstrated by 5% or more of controls (normal error), '2' if observed in less than 5% (borderline error); and '3' if they were unique to the ABI group (abnormal error). Using a weighting system to recalibrate error scores to reflect qualitative differences between groups resulted in a large improvement in discriminant validity, from correctly classifying 44 to 82% of cases. In addition, predictive validity was also enhanced with improved correlations evident between MET-SV test scores and other measures of executive impairment.

Given the important issue of context, the current study sought to develop and critically evaluate a method to assist interpretation of the results from NBD assessment instruments. The principal goal was to attempt to provide a means of determining the likely extent to which measured outcomes represent autonomous vs. environment dependent functions. Previously, Swan and Alderman [21] described the Neurobehavioural Expectations Scale, which enabled change in measures of aggression over time captured from the OAS-MNR to be interpreted against the context of a measure of the level of intensity of the rehabilitation programme. Whilst useful, this method was

designed to be aid interpretation of a focal measure, rather than a global assessment of NBD symptoms and behaviours. A limitation is that items in the measure are specific to the individuals rehabilitation programme, and is applied retrospectively, after discharge. What is ideally required is a method that assists interpretation of results from an instrument that provides measures of the rich variety of symptoms of NBD, rather than a single aspect, that can be applied at any stage in rehabilitation.

This study will consider application of such a method to facilitate further understanding of the outputs from a global measure of NBD, the 'St Andrew's – Swansea Neurobehavioural Outcome Scale' (SASNOS) [22]. SASNOS was designed as a response to the results of an earlier review of NBD measures conducted by the authors, which highlighted a number of concerns with some existing measures [11]. Specifically, the study aimed to (a) develop a method of determining the extent to which improved function and reduced symptoms of NBD are attributable to context-dependent support using a supplementary scoring system that weights standard SASNOS scores to reflect this, and (b) determine how interpretation of dissonance between standard and weighted scores can be used to assist clinical decision making. To achieve this, a mixed methods approach was employed utilising: a review of SASNOS assessments that had employed the supplementary scoring system drawn from a sample of cases participating in NbR by an expert panel; description of a representative case example; and consideration of the results of an end-user survey.

METHOD

Participants

Review of SASNOS data – An expert panel led by the first author examined an anonymous database containing results from ABI outcome measures, including the SASNOS, in order to identify dependency profile categories arising from the supplementary scoring system which are subsequently employed to identify the extent of context-dependent support provided. The panel

consisted of senior psychologists working in neurobehavioural services in the UK, all of whom were experienced in using, scoring and interpreting the SASNOS. The database was compiled as a consequence of routine service evaluation of a neurobehavioural rehabilitation programme encompassing multiple sites during the period April 2015 – March 2016. It contained some basic information about programme participants who had been assessed on a basket of outcome measures, including the SASNOS, together with scores obtained. Assessments were made by members of the clinical team delivering rehabilitation to specific individuals in the database. These included medical staff, psychologists, therapists and nurses. Outcome measures were routinely completed in the service to assist with setting goals, tracking response to rehabilitation and discharge planning. Clinicians completed the measures as a group in specific sessions designated for this purpose.

Participant data was scrutinised by the expert panel providing: an individual had received a diagnosis of acquired brain injury; there was no additional diagnosis of a progressive neurological condition; they had been rated at least twice during the period records were sampled; and that ratings from the additional supplementary scoring system constructed by the authors had been completed for each SASNOS assessment (see 'Instruments' below).

Fifty participants met these inclusion criteria. As the database was anonymous only limited information regarding individual participants was available. The majority of the sample was male (76.7%). Mean age was 45.7 years (SD = 13.7, range 18-73). The principal cause of ABI was trauma (51.2%). Others included hypoxia (20.9%), cerebrovascular accident (16.3%), infection (2.3%) and alcohol induced brain injury (2.3%). In 7% of cases, cause of ABI was unknown. The majority of programme participants were not legally detained for the purposes of treatment and rehabilitation (62.8%).

All but two rehabilitation participants were rated on one or more of the five SASNOS domains as having more symptoms of NBD than would be expected in the general population (standardised score < 40: p4, 23).

Representative case study – To illustrate how the derived dependency profiles enhance interpretation of any contextual influence on NBD symptoms inherent to the rehabilitation environment, a representative case study is described. Whilst this draws heavily on ratings made regarding a single, actual recipient of NbR, SASNOS results and factual details were altered to ensure anonymity.

End user survey — Finally, to confirm validity of the weighted ratings in capturing the impact of context-dependent support received on observed symptoms of NBD, a questionnaire¹ was administered to a panel of anonymous SASNOS users. Ten potential respondents were randomly identified from a database of known users, comprising clinicians working in neurobehavioural rehabilitation units in the UK (psychologists who regularly administer SASNOS in their clinical work).

Instruments

The St Andrew's – Swansea Neurobehavioural Outcome Scale (SASNOS) – SASNOS was developed by Alderman, Wood and Williams [22] in response to the findings of their previous review of existing measures of NBD which suggested these were problematic [11]. SASNOS was created specifically for use in ABI using a conceptual framework underpinned by the WHO ICF to overcome these difficulties in order to provide a valid, reliable instrument for the meaningful measurement of NBD that can be employed for clinical and research purposes. Construction utilised methods from both classical test theory and item response theory (including Rasch analysis). It contains 49 items that capture five major domains of NBD: Interpersonal Relationships; Cognition; Inhibition; Aggression; and

¹ Copy available on request from the first author

Communication. Each domain has 2-3 subdomains (for example, Aggression consists of *provocative behaviour*, *irritability* and *overt aggression*). Items comprise a statement regarding a symptom of NBD, rated using a seven-point scale with written anchors ('never' to 'always'). Both 'other' and 'self' completion versions are available. In a rehabilitation context, participants are typically first assessed using the 'other' version during the third week of admission, repeated at major reviews of progress, and at discharge, and follows observation of a person over a two week period. A major strength of SASNOS is availability of ratings of neurologically healthy people, facilitating identification of NBD symptoms in individuals with ABI more prevalent than amongst the general population. Ratings are transformed to standard scores with a mean of 50 and standard deviation of 10; higher scores reflect greater perception of ability and fewer symptoms of NBD.

SASNOS has robust psychometric properties; inter-rater and test-retest reliability have been established, and multiple indicators of validity demonstrated (including content, construct, convergent, divergent and discriminant validity) [22]. In addition to reliability and validity, the authors recently completed the 'holy trinity' of psychometric properties of outcome measures by reporting on responsiveness of the SASNOS [23]. They described a number of responsiveness indicators to assist clinicians and researchers in interpreting significance and meaning of change in scores on repeat assessment. SASNOS is free to access and full user support is available (see https://projects.swan.ac.uk/sasnos).

SASNOS Supplementary Scoring System — To capture information regarding the effects of context-dependent support, standard SASNOS scores were recalibrated to reflect the degree of help or support rehabilitation participants received for the management of each of the 49 NBD symptoms using the supplementary scoring system developed by the authors. An additional dependency rating was assigned to each item using the guidelines in table 1: '1 — no help or support'; '2 — receives help or support'; '3 — receives a structured programme/intervention'. Recalibrated standard scores are

referred to as weighted scores hereafter to clearly reflect they have been the subject of modification.

<TABLE 1 ABOUT HERE>

Weighted scores are determined using the following expression:

Weighted score = standard score / (sum of dependency ratings / total number of items)

For ease of reference, the number of items for each of the principal scores from the SASNOS is outlined in table 2. For each standard score, weighting either has no effect (where the average dependency rating = 1.0) or it is reduced (where average dependency rating > 1.0).

<TABLE 2 ABOUT HERE>

To illustrate calculation of weighted scores, consider the following example regarding the SASNOS Aggression domain. There are 12 items in total in this domain (see table 2); the standard score obtained was 43.3, and the sum of the twelve ratings of dependency for each item using the supplementary scoring system is 27. This gives:

Weighted score aggression = 43.3 / (27 / 12) = 19.2

The reduced score, and the discrepancy with the standard score gives some indication that environmental support is important in underpinning the apparently 'normal' rating, with negative implications if this were to be withdrawn or unavailable in a new context.

End user survey — The first page of the questionnaire presented an overview of the study, information on consent and data protection arrangements, and a full description of the supplementary scoring system, illustrated by means of a line graph of fictitious ratings to demonstrate both the standard and weighted scores in an individual case. The second page consisted of four questions. Questions 1 and 2 were designed to confirm the expertise (through experience) of respondents through their responses to the items which concerned the usefulness of the SASNOS weighted scoring system: (1) 'Approximately how many times have you administered and reported ratings from the SASNOS?' (response categories were: 0, 1-5, 6-10, 10-15, 16-20 and 'over 20), and (2) 'Have you utilised the additional dependency ratings?' (Yes/No). Questions 3 and 4 were directly concerned with face and construct validity: (3) 'How useful are the weighted scores in reflecting contextual dependency (true autonomy) of people with ABI you have assessed with the SASNOS?' (5-point scale: Not at All Useful — Extremely Useful), and (4) 'What, if any, are the benefits to your clinical practice of weighting SASNOS scores using the dependency ratings in assessment and reporting of NBD and social handicap?'.

Analysis

Regarding the review of SASNOS assessments pertaining to the 50 rehabilitation participants, the expert panel studied the pattern of relationships between standard and weighted scores, and reached consensus on the number of descriptive dependency profiles required to satisfactorily summarise these. The descriptive case study did not require analysis.

Regarding the end user survey, open ended responses to question 4 were reviewed by the first author (NA) to identify and report themes. Replicating the procedure used by Tam, McKay, Sloan and Ponsford [5], NA documented initial patterns and meaningful elements of the raw data (codes), which were cross-checked and refined by the second author (CW). These codes were assembled and categorised to produce overarching themes, each with sub-themes as appropriate. Resultant themes

were then reviewed (team discussion, cross checking of transcripts and themes) to ensure that they reflected the coded texts and were representative of the data set.

RESULTS

Identification of domain and dependency profile categories

standard and weighted scores, a strong, positive correlation between SASNOS domains was assumed, that is, all result in an equivalent score. In reality, equivalence across scores is not necessarily expected; Alderman, Wood and Williams [10] reported variable correlations between the five SASNOS domains, ranging from .14 to .69. For completeness, the number and frequency of domain profile categories within the sample were determined using the first assessment completed for each participant. Profiles were extracted depending on the number of domains that resulted in a standard score less than one standard deviation below the mean for controls (<40) (summarised in table 3). A total of ten unique combinations of SASNOS domain profile scores were found. By far the most prevalent was where standard scores for Interpersonal Behaviour and Cognition both fell below the cut off criteria (66%). In contrast, the frequency of other unique profiles was idiosyncratic, ranging from 2-6% of the total sample. However, the majority of the sample (93%) had NBD profiles that included both Interpersonal Behaviour and Cognition (note, standard scores are not dependent on the number of individual items).

Dependency profile categories – The expert panel concluded there were three dependency profile categories that are directly used to determine context-dependent support. These are described below together with illustrative examples.

1) 'Normal/Independent' - where standard and weighted score(s) fall within or above the normal range for neurologically healthy controls (≥40) (figure 1). Profile scores in this category suggest

symptoms of NBD are comparable with those occurring within the neurologically healthy population.

In a rehabilitation context, this finding may be evidence of modification of dynamic, flexible drivers of NBD that are independent of the rehabilitation environment.

<FIGURE 1 ABOUT HERE>

2) 'Normal/Dependent' - where standard score(s) lay within or above the expected normal range, but weighted scores fall below this (figure 2). Standard scores suggest symptoms of NBD are comparable with those observed in the general population; however, weighted scores do not map onto these in the same way as they do in the 'normal/independent' profile. Instead, there is a notable dissonance between standard and weighted scores, with the former being above cut off and the latter below this. This pattern suggests lack of NBD symptoms is dependent on the degree of context-specific support in operation at the time of assessment. The implication of this profile is that NBD is driven by static, fixed factors whose disabling influence is circumvented through features in the environment manipulated for this purpose. Two likely considerations are that either further work needs to be undertaken in the rehabilitation setting to increase autonomy; or that those structures and interventions maintaining the person at that level require careful replication in future placements in order to sustain inhibition of NBD symptoms.

<FIGURE 2 ABOUT HERE>

3) 'Abnormal/Review' - where both standard and weighted scores fall below the normal range (figure 3). This profile reflects that symptoms of NBD are more frequent/severe than those observed in the neurologically healthy population, and that social handicap challenging autonomy remains a barrier to personal autonomy. Clearly in these cases provision of effective interventions to address NBD is required regardless of whether drivers of the NBD symptoms observed are attributable to

static/fixed or flexible/dynamic factors. In cases where weighted scores map closely onto standard scores, average dependency ratings will equate close to 1.0, reflecting support and interventions are lacking. Here, decision making regarding implementing treatment programmes will be the key consideration (Figure 3 - 'Weighted score a'). Conversely, if support is already being given, weighted scores will be lower (because average dependency ratings will typically fall between '2' and '3') and there will be an appreciable distance between the two plots. In this case, existing interventions are likely to require review as they are ineffective (figure 3 - 'Weighted score b').

<FIGURE 3 ABOUT HERE>

2) Representative Case Study

Overview - RF sustained a very severe TBI aged 19 years of age as a result of a motor vehicle accident. CT scans performed shortly after admission to hospital revealed diffuse damage throughout, together with prominent bilateral frontal and temporal lobe focal lesions. Initial Glasgow Coma Scale score was seven, and the subsequent period of post-traumatic amnesia exceeded two weeks. He was discharged from hospital after three weeks, having been described as making a 'good' physical recovery.

Psychosocial, behavioural and emotional difficulties emerged over the course of the next six months. In contrast to his premorbid personality, family members described RF as irritable, lacking empathy, with poor drive and initiative. He also presented with neurocognitive impairment, particularly regarding attention, memory and executive functioning. RF was unable to return to work or otherwise engage in sustained, productive activity. As his behaviour in the community deteriorated, RF experienced increased contact with police and the criminal justice system, resulting in a number of short-term custodial sentences. Specialist assessment eventually resulted in admission to a neurobehavioural rehabilitation facility four years after sustaining TBI.

Initial assessment shortly after admission revealed a profile in which standard scores reflecting symptoms of NBD were 1-2 standard deviations below that expected in neurologically healthy controls for four of the five main domains, with only Communication falling in the expected range (Domain Profile Category 4 in table 3). RF subsequently spent 18 months receiving intensive NbR, progressing during this time within the care pathway to the point where he was being successfully sustained in his own flat within the facility. It was at this point that comprehensive reassessment was undertaken, including the SASNOS. Results are presented in figures 4 and 5.

<FIGURES 4 & 5 ABOUT HERE>

SASNOS assessment & interpretation - Standard scores for the total score and five major domains are presented in figure 4. These range from 40.9 – 65.7, falling within the expected limits for neurologically healthy controls, with the exception of Inhibition, which exceeded one standard deviation above the mean. Standard scores reflected an absence of symptoms of NBD within the context of the rehabilitation unit. Figure 5 shows the standard scores for the twelve subdomains. Again, it can clearly be seen most of these fell within or just above the expected range for neurologically healthy controls. The exceptions were social interaction and relationships which achieved standard scores just below one standard deviation from the mean (39.4, 38.1).

Examination of the individual items comprising these subdomains revealed that lower ratings regarding recognising other people's feelings, forming close meaningful relationships, and displaying warmth and compassion, underpinned these slightly deflated scores. Despite this, results of assessment suggested the extent of symptoms of NBD were largely consistent with that observed in the general population. Taken at face value, the observable extent of NDB, together with RF's successful trajectory through the rehabilitation care pathway, could reasonably be interpreted as evidence to support discharge from the service and return to the community.

However, figures 4 and 5 also show weighted scores which imply a different interpretation of results. Two of the three dependency profile categories described earlier apply to RF's results. First, both standard and weighted scores for two domains fell within or above the normal range; in both of these, all items received a dependency rating of 1.0, with the resulting mean dependency score (also one) exerting no change to standard scores. Dependency scores of 1.0 were assigned to all these items by the clinical team as RF received no help or support for any of the symptoms of NBD described. This pattern is consistent with the 'Normal/Independent' profile in which scores achieved are compatible with those of neurologically healthy people, and both standard and weighted scores map closely onto each other. This profile implies lack of symptoms is not a function of context-dependent support.

Second, whilst standard scores fall within the normal range for the remaining domain scores and total SASNOS score, figure 4 confirms that weighted scores fall well expected levels (1-3 SD). The two sets of scores do not map precisely onto one another in this example, as some items were given a dependency rating of two or three, resulting in a mean score greater than one, and a reduction from the standard score as a consequence. As standard scores fall in the expected range, the dependency profile category applicable here is 'Normal/Dependent'. As argued earlier, this profile suggests that whilst NBD symptoms are not observed beyond that evident in the normal population, this is in part attributable to the degree of context-dependent support available at the time of assessment. As this was a rehabilitation setting, this almost certainly reflects the degree of spontaneous and prescribed support provided by the physical environment and the clinical team. Further detail regarding the subdomains is evident in figure 5, which strongly suggests NBD symptoms that characterise Interpersonal Behaviour as a whole and those consistent with Aggression, especially *provocative behaviour*, are well managed by support in place within the rehabilitation environment, with the clear implication that deterioration would take place if this were not the case.

However, despite the presence of 'Normal/Dependent' profile categories, the decision was made by the referring authority that RF should be discharged from NbR and managed in a community hostel in the community, against the advice of the rehabilitation team; there was no specific ABI expertise in this service and insufficient resources available to replicate the programmes and structures put in place. Unfortunately, and as predicted, RF became aggressive, assaulted hostel staff, and the placement broke down within four days. He was subsequently returned to NbR and the previous interventions used to manage NBD symptoms successfully re-implemented.

3) Validity

Expertise of SASNOS Users Completing the Survey — Familiarity in administering and interpreting the SASNOS supplementary scoring system were the main indices used to quantify the 'expertise' of respondents; 80% had administered SASNOS ≥20 occasions, with the remaining 20% having used it in on '6-10' occasions. All respondents (100%) indicated they were experienced in utilising the new supplementary scoring system in order to transform standard to weighted scores.

Usefulness of the weighting system — Face validity was determined from the responses to the following item: "How useful are the weighted scores in reflecting contextual dependency (true autonomy) of people with ABI you have assessed with the SASNOS?", 80% indicated 'extremely useful', and the remaining 20% 'quite useful'.

Additional information regarding validity was gleaned from the free text responses to questionnaire item 4: "What, if any, are the benefits to your clinical practice of weighting SASNOS scores using the dependency ratings in assessment and reporting of neurobehavioural disability and social handicap?". Four key themes emerged:

1) Benefits to interpretation of SASNOS scores: Respondents agreed that standard scores could lead to underestimation of the potential future negative impact of symptoms of NBD:

Through using the dependency ratings, we get a truer reflection of the patient's NBD.

The dependency ratings make SASNOS ratings much clearer for staff. Before the dependency ratings were introduced, staff would rate the service user's functioning based on their current presentation, with staff support. This would result in an underestimation of a person's neurobehavioural disability.

Responses indicated that weighting standard scores to take into account the positive impact of the rehabilitation environment in reducing NBD symptoms was advantageous in reflecting the effect of context:

It is helpful to understand the context in which behaviour takes place. So, for example, the person may function well but only because of the programmes and structure put in place by staff which limit their behavioural impact.

Rehabilitation is an artificial environment designed to improve challenging behaviours among other things. Dependency ratings show how a patient would perform outside of the artificial environment.

2) Demonstrating effectiveness of neurorehabilitation at individual and service levels: Respondents reported how weighting standard scores further enhanced feedback on individual progress within neurorehabilitation:

In an ideal world, it would nicely represent progress in rehabilitation if the standard scores are increasing over time and the gap between standard and weighted ratings reduce also, to further reflect progress and increase in the individual's independence.

Respondents also commented that concurrent increase in both standard and weighted scores, mirroring reduction in NBD symptoms and increasing autonomy regarding these, were also useful in validating benefits of NbR:

The support ratings have been useful to show the impact of neurobehavioral rehabilitation on symptoms of neurobehavioural disability.

The weighted severity ratings are useful to us in demonstrating the role of the support and structure from the neurobehavioural approach in reducing the effects of NBD on the individual.

Reporting progress in this way was also felt to be advantageous for demonstrating effectiveness of services:

Allowed us to show external professionals and funders how someone was benefitting from support from the service.

3) Clinical decision making and planning for the future: Respondents indicated that consideration of both standard and weighted scores were helpful in short-term goal planning in rehabilitation:

Allowed the team to see whether an individual was making progress independently, or whether they were receiving a great amount of support in certain areas. We could then discuss how to help someone become more independent in these areas if necessary.

The support ratings inform clinical review and provide information necessary to the team when changes in care plans are considered.

In addition, having an understanding of the impact of the rehabilitation context on the extent of NBD symptoms observed encouraged respondents to adopt a long-term view regarding the degree of autonomy they could achieve with their patients, along with the level of resource patients would need to maintain them at the optimum level post-discharge:

Using the dependency ratings encourages clinicians to think about the range of interventions in the current rehabilitation programme and whether they directly address domains in which the person functions well in the current setting but not in the community setting or has difficulties in functioning in all settings. These areas may affect the person's quality of life and present barriers to discharge into community settings; therefore they importantly drive the clinical team's focus to work towards discharge into a community setting from the early stages of admission to the service.

Dependency weightings provide a useful framework for an informed analysis of the patients current needs to be developed by the clinical team. This helps with discharge planning including raising awareness of the patients functioning to all involved professionals, safe management of risk areas/areas for further treatment (which may not necessitate inpatient treatment) and contingency plans with the goal of ensuring a safe and sustainable discharge.

The importance of the last point was made several times. Getting external agencies on-board with the anticipated future level of care and resources required to minimise the effects of NBD, including

those who fund services, is crucial. They also can help mitigate against premature discharge from services:

The weighted SASNOS graphs effectively demonstrate to commissioners the support service users require, and estimates how they are likely to function if this support were to be withdrawn if the parson was discharged from the service too soon.

From using the dependency ratings clinically, commissioners and other professionals have found their use effective in highlighting patients current and future needs in a clear and unambiguous manner.

The support ratings have been used by external clinicians at panel to demonstrate continued need for funding.

The potential usefulness of the weighted scores in risk assessment was also noted.

The dependency ratings can be useful in assessing clinical risk when patients are being discharged from services, specifically by highlighting the areas where the person needs external support and may deteriorate in functioning without this support.

4) Improving reporting and feedback: enhanced reporting and using results to feedback to relatives was further highlighted.

It has been really useful in (Care Programme Approach) reviews to demonstrate the current need/benefit for the individual to be in such a placement and I have found (it) has given reassurance to family members also, within these meetings.

It allows us to comment on the expected level of NBD of an individual without the support provided from staff or a structured rehabilitation programme and therefore identify areas which would be potential sources of handicap. This has proven to be particularly useful to report on in CPA reports.

DISCUSSION

In this paper, possible confounding effects of context on assessments relying on ratings of global abilities were highlighted. It was argued that results from assessment reflect functioning in the 'here and now', and that further evaluation is required to reliably predict longevity and generalisation of findings. A supplementary scoring system to enable this was described, which weights standard scores derived from the SASNOS in an attempt to show the extent to which lack of NBD symptoms are dependent on support from the rehabilitation environment.

The utility and usefulness of weighting scores using this system was investigated. Firstly, expert panel review concluded that the extent of any dissonance between standard and weighted SASNOS scores can be meaningfully interpreted by applying one of three profile types. Secondly, validity of weighting scores was explored through qualitative analysis of a questionnaire completed by SASNOS users. Results supported application of the additional ratings. Users indicated adjusting standard scores to reflect dependence on the environment is beneficial; reduces risk of underestimating the extent of NBD in other settings; facilitates understanding of whether reduction in NBD symptoms is attributable to modification of dynamic vs. static factors; provides further evidence of the benefits of NbR; and makes a valuable contribution to rehabilitation, especially goal planning, evaluation and assessment of future needs. Finally, a representative descriptive case study further illustrated both the application and the benefits of applying the supplementary scoring system.

The clinical implications arising from weighting standard scores are especially noteworthy and what drove the work reported here. In particular, applying the dependency profile categories to the SASNOS total score, five domain and 13 subdomain scores enables clinicians to quickly make an appreciation of the current needs, response to treatment and possible future goals required of an individual rehabilitation participant. Standard SASNOS ratings of 40 or more are compatible with measurement of NBD symptoms observed amongst the general population. Each standard/weighted score pairing categorised as 'Normal/Independent' can reasonably be interpreted as reflecting lack of NBD symptoms that is not dependent on support for that individual from the environment. To put this finding in a wider context, previous assessment of the same individual may have resulted in the standard/weighted score pairing for a domain or subdomain being categorised as either 'Normal/Dependent' or 'Abnormal/Review'. In either case, the subsequent shift to 'Normal/Independent' demonstrates a positive response to rehabilitation. Both first and repeat assessments suggest absence of NBD symptoms. However, in the former, the 'Normal/Dependent' classification reflects this was initially because of the support available in the environment; a characteristic of NbR services is they are highly structured, and that presence of these structures can circumvent factors driving NBD, resulting in very rapid reduction in symptoms following admission [8]. Conversely, the initial 'Abnormal/Review' dependency profile may be more typical of environments that lack these structures, with both a low standard /weighted score pairing reflecting significant presence of NBD symptoms and lack of support to manage these. In both cases, the shift to a 'Normal/Dependent' score pairing implies the drivers of NBD were dynamic and flexible, and therefore amenable to rehabilitation input. Furthermore, gains incurred are likely to be maintained independently of environmental support. Conversely, progression to or maintenance of a 'Normal/Dependent' profile strongly suggests absence of NBD symptoms remains reliant on continued environmental support, and by implication the drivers of this are static and fixed. When this is the case, environmental support at the level in operation at the time of assessment is likely to be a long-term provision.

The various permutations and clinical implications arising from dependency profiles on assessment and reassessment are summarised in figure 6, along with brief suggestions regarding interpretation and recommendations for action.

< FIGURE 6 ABOUT HERE >

Instruments that are responsive to change incurred through rehabilitation such as the SASNOS should be being employed to inform clinical decision making. In NbR services, SASNOS scores that fall in the same range as the general population can reasonably appear indicative that discharge is appropriate. However, when drivers of NBD are static and fixed, apparent resolution of NBD symptoms is most likely to be a function of the support provided. In such cases, there is a risk that this level of input will be lost following discharge. This scenario is one with which the authors are well acquainted, but in their experience being able to demonstrate 'Normal/Dependent' domain profiles helps reduce such risk. Furthermore, this increases the likelihood that appropriate levels of support will be maintained by external agencies tasked with providing future care.

It is anticipated that dependency profile categories will provide a shorthand means of highlighting the extent to which changes in SASNOS scores observed in rehabilitation are dependent on environmental support. A further finding worthy of note is that NBD is variable, and to a greater or lesser extent, the principal clusters of symptoms, as evidenced through the SASNOS domains, are independent. Thus, there is no expectation that the types of disability attributable to NBD are replicated exactly across individuals. The domain profile categories verified by the expert panel in the current sample suggest that some categories of symptoms of NBD are highly characteristic of ABI whilst others are more idiosyncratic. For example, most of the sample presented with NBD symptoms relating to Interpersonal Behaviour and Cognition. In contrast, evidence of clinical

problems with Aggression, Inhibition and Communication were not endemic. Scrutiny of the frequency of SASNOS domain profiles in other samples of people with ABI would be helpful in describing outcomes. Similar variety regarding causation should also be expected, as drivers of NBD are non-homogenous and complex. Indeed, in individual cases symptoms of one domain may be primarily attributable to static factors, whilst others are the product of dynamic factors. Weighting standard scores and determining relationships between domain and dependency profile categories in relation to treatment outcomes may also be instructive in highlighting rehabilitation participants future needs.

Study limitations and future research

The current study is not without limitations. At this stage in its development it cannot be conclusively demonstrated that weighted SASNOS scores genuinely map onto what standard scores would be achieved beyond the rehabilitation setting. The extent of any differences between standardised and weighted SASNOS scores is a function of the range of the modifying factor, in this case the mean dependency rating from the supplementary scoring system. Whilst it is not possible to confirm predictive accuracy, the current approach is likely to be conservative as only a three-point scale is employed. The anchor point reflecting minimal context-dependent support needs to be fixed at a value of 1.0, as this results in equivalent weighted and standard scores. A future study could conduct a longitudinal follow-up of people with ABI after discharge from services in which they are assessed, determining predictive accuracy by comparing weighted scores achieved in rehabilitation with standard scores in the post-discharge environment. Nevertheless, the main purpose of the supplementary scoring system explored at this early stage of development was to determine if there were any benefits to clinical decision making from discriminating the three dependency profile categories. Encouragingly, the views expressed by SASNOS end-users in the survey clearly highlighted an array of advantages to recalibrating SASNOS scores as a way of conveying the impact of assistance received, supporting the validity and usefulness of the approach. For example, endusers were of the view that consideration of standardised and weighted scores was helpful in giving feedback on progress within rehabilitation, for short-term goal planning and in judging any potential future negative impact on NBD symptoms, and for reporting and using assessment scores to feedback to all interested parties.

Another limiting factor at this stage concerns generalisation of the results to populations of different cultural backgrounds to the UK sample of convenience employed here. At the time of writing, various translations of the SASNOS have become available (Welsh, French, German and Spanish: see website for details https://projects.swan.ac.uk/sasnos) which along with the English version will facilitate further investigation of any effects of culture on the existing normative data and applicability of the instrument, including that described in the current paper.

Another area of potential research will be to confirm a wider range of psychometric properties of the supplementary scoring system. In addition to predictive validity, other psychometric properties could be explored, some relatively easily, such as inter-rater and test-retest reliability. Whilst this study suggests clinicians perceive the supplementary scoring system favourably, collecting equivalent information from people with ABI, their families, those responsible for funding rehabilitation and service providers, would make a further valuable contribution to validity and in determining the clinical value of recalibrating standard SASNOS scores using the method suggested here.

In conclusion, a supplementary scoring system has been proposed to overcome difficulties in conveying the impact of context-dependent support when using standardised assessment measures. It is anticipated this additional functionality will enhance clinical practice, and further support the contention that SASNOS provides a valid and reliable measure of NBD, especially as a means of determining rehabilitation outcomes and in care planning.

DECLERATIONS OF INTEREST

The authors report no declarations of interest.

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FIGURE CAPTIONS

Figure 1

SASNOS Domain Dependency Profile Category 'Normal/Independent'. (Key to axis labels: 'IB – Interpersonal Behaviour', 'Cog – Cognition', 'Inh – Inhibition', 'Agg – Aggression', 'Com – Communication'.)

Figure 2

SASNOS Domain Dependency Profile Category 'Normal/Dependent'. (Key to axis labels: 'IB – Interpersonal Behaviour', 'Cog – Cognition', 'Inh – Inhibition', 'Agg – Aggression', 'Com – Communication'.)

Figure 3

SASNOS Domain Dependency Profile Category 'Abnormal/Review'. (Key to axis labels: 'IB – Interpersonal Behaviour', 'Cog – Cognition', 'Inh – Inhibition', 'Agg – Aggression', 'Com – Communication'.)

Figure 4

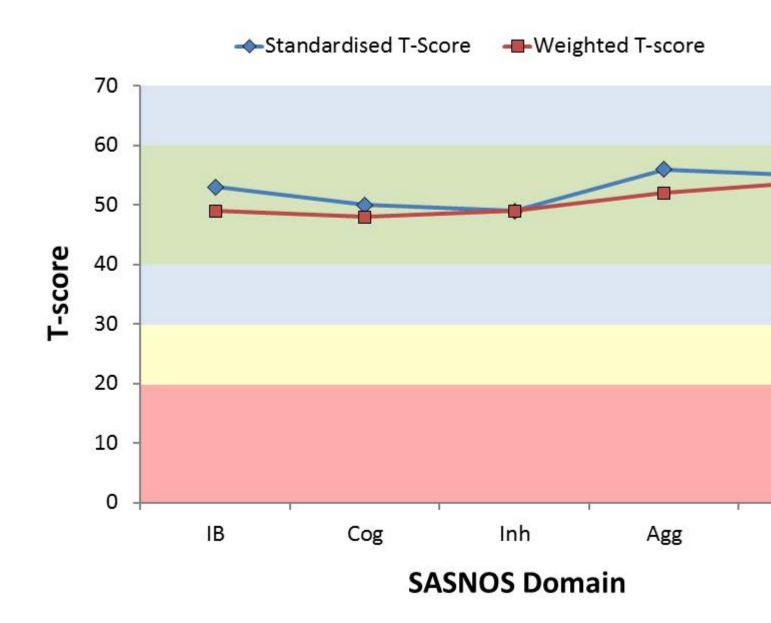
Case RF SASNOS Total and Domain Scores, comparing standardised and weighted scores. (Key to axis labels: 'IB – Interpersonal Behaviour', 'Cog – Cognition', 'Inh – Inhibition', 'Agg – Aggression', 'Com – Communication'.)

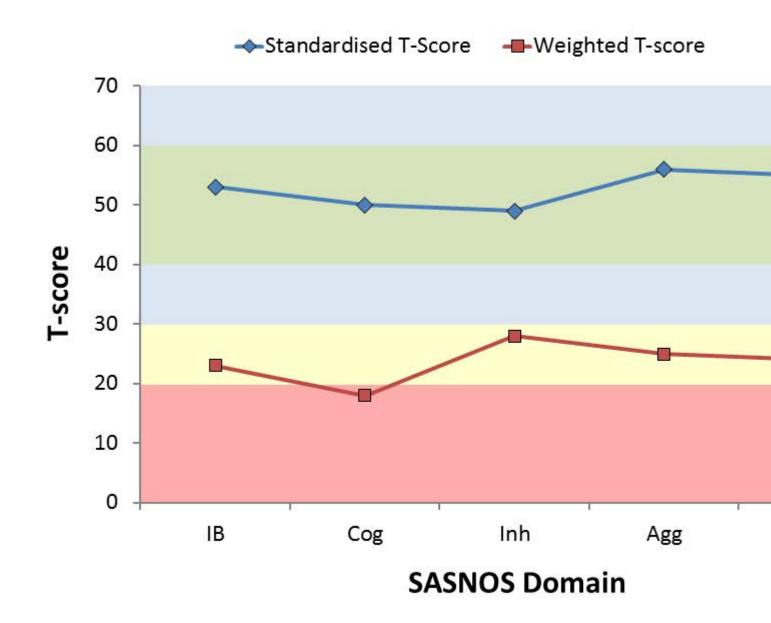
Figure 5

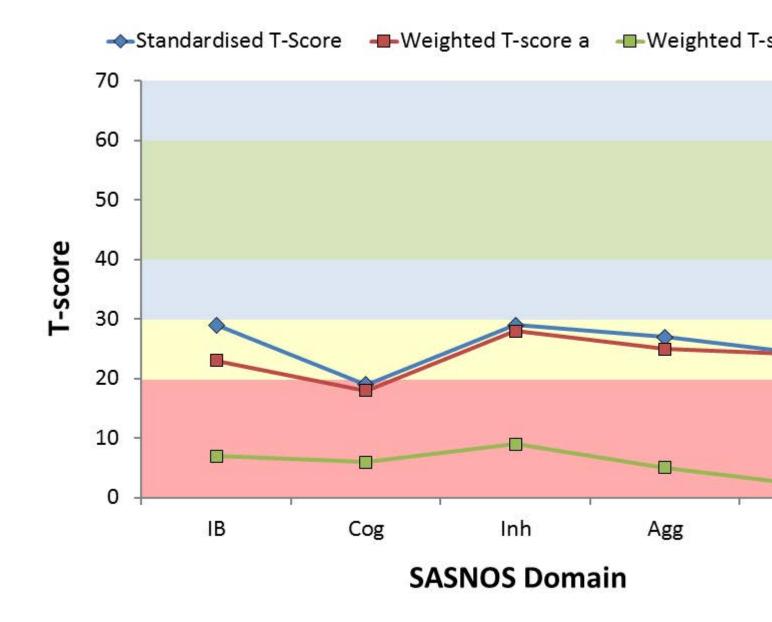
Case RF SASNOS Subdomain Scores, comparing standardised and weighted scores. (Key to axis labels: 'IB – Interpersonal Behaviour', 'Cog – Cognition', 'Inh – Inhibition', 'Agg – Aggression', 'Com – Communication'.)

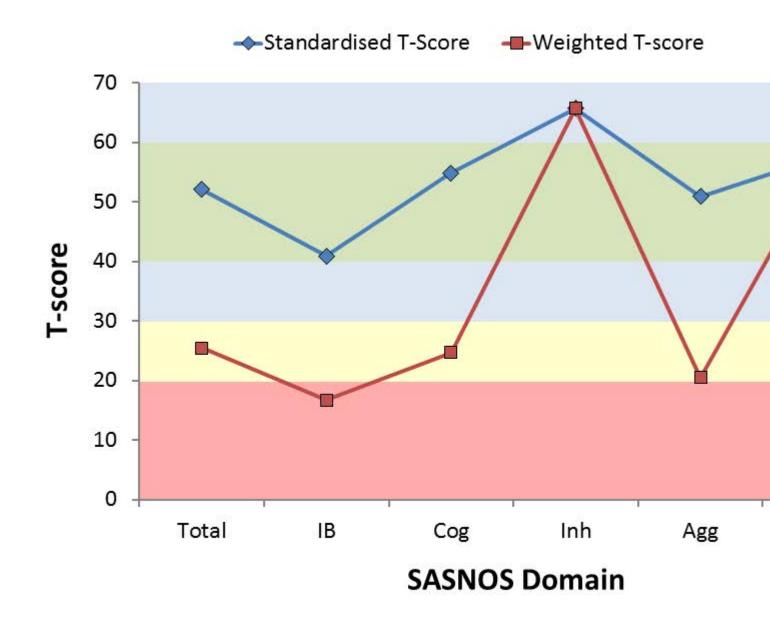
Figure 6

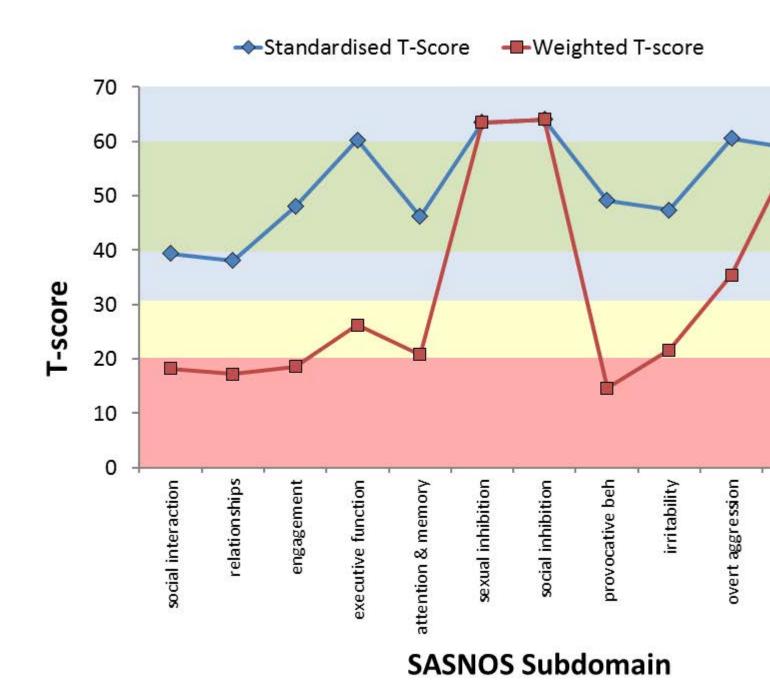
Clinical implications of SASNOS dependency profile categories: suggestions for meaning and interpretation.











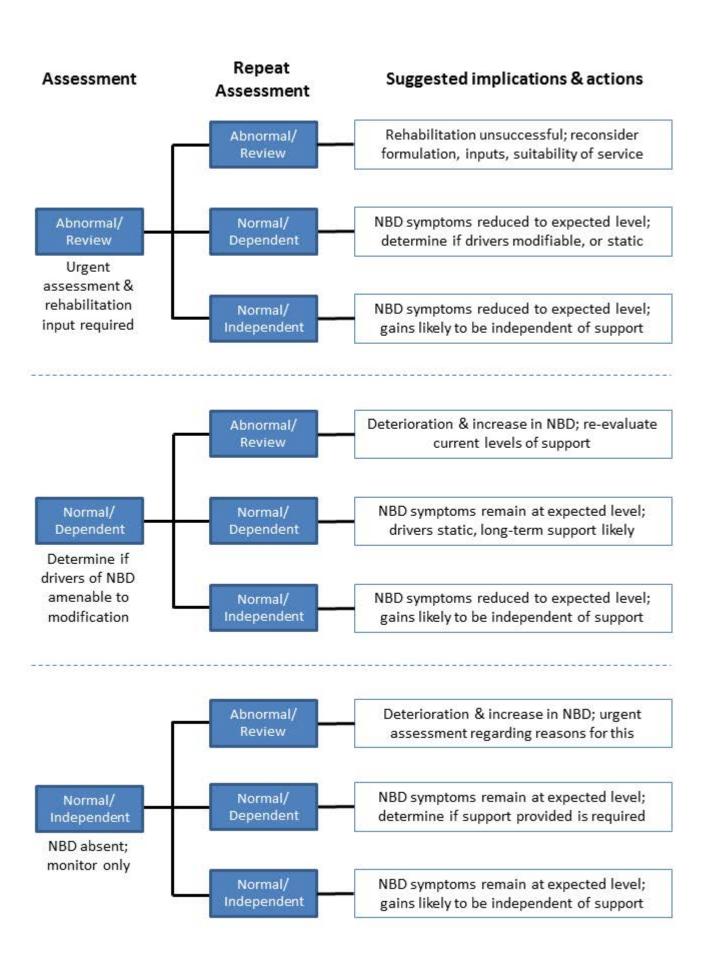


Table 1: Dependency rating response anchors

Dependency Rating	Response Anchors
1. No help or support	The person is independent in the skill, for example planning activities, or behaviour, for example managing anger, and does not need any input from staff or carers regarding this (obviously this may still be dependent to an extent on the environment, for example there is a timetable on the wall etc., but nevertheless no additional assistance is given). Also rate '1' if the need is per '2' or '3' (as below) but neither is available at the time of rating (unmet need).
2. Receives help or support	The person is given intermittent guidance to complete some tasks, staff may need to intervene to curtail inappropriate behaviour. Note they may be in need of '3' but this is unavailable (partially met need).
3. Receives a structured programme/intervention	The person is the recipient of a prescribed programme of intervention to maintain a skill or manage behaviour, for example formal washing and dressing programme, or a behaviour modification intervention

Table 2: SASNOS number of items by domain and subdomain

T-score	Number	T-score relating to	Number	T-score relating	Number
relating to	items		items	to	items
Total sum	49	Interpersonal relationships	15	Social interaction	5
of ratings					
				Relationships	5
				Engagement	5
		Cognition	12	Executive	6
				function	
				Attention &	6
				Memory	
		Inhibition	6	Sexual	3
				Social	3
		Aggression	12	Provocative	5
				behaviour	
				Irritability	4
				Overt aggression	3
		Communication	4	Speech &	2
				language	
				Mental state	2

Table 3: Type and frequency of SASNOS Domain Profile Categories

Domain Profile Category	IB	Cog	Inh	Agg	Com	Number	Percentage
1	Х	х	Х	Х	Х	1	2
2	Х	x				33	66
3	x	x			x	1	2
4	x	x	x	x		1	2
5						2	4
6	x	x	x			3	6
7	x	x	x		x	2	4
8	Х	x		x		3	6
9		x				3	6
10	Х					1	2

NB: 'IB – Interpersonal Behaviour', 'Cog – Cognition', 'Inh – Inhibition', 'Agg – Aggression', 'Com – Communication'.