Outcome Measurement project

September 2012
Forward

This project was initiated from within the membership of Communication Matters. Currently there are few resources that support practitioners, people who use augmentative and alternative communication and their families to demonstrate change or development of communication skills. Current service provision across the UK is required to demonstrate effectiveness and efficiency of provision. Outcome Measurement tools are recognised as a means of demonstrating efficacy. There are no outcome measurement tools in use in the UK that were designed from a perspective of aided communication needs. The project team was tasked with reviewing a range of tools and measures commonly used in the UK and appraising them in terms of their usefulness to aided communication measurement.

This document is offered as a guide to the reader. It is not exhaustive but has a multi-disciplinary focus. This focus reflects the composition of the working party who must be congratulated for their enthusiasm and commitment to the production of this 'first edition'.

Dr Janice Murray
Chair, Communication Matters
September 2012
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Introduction

Communication Matters (CM) is a charitable organisation aiming to assist those who need to use augmentative and alternative communication (AAC) (see footnote) to facilitate achievement of their full potential.

CM initiated a project on outcome measurement (OM) with the aim of providing information to service providers and users in order to equip them with knowledge about tools that are appropriate to identify change associated with services and an individual’s communication skills.

The outcomes measurement project group chaired by Gary Derwent (Occupational Therapist) and Janice Murray (Speech and Language Therapist) included the following members:

- Ruth McMorran (teacher)
- Vicky Styles (SLT)
- Claire Hayward (OT)
- Mary Gilbert (SLT)
- Jenny Herd (parent)
- Jackie Ayres (OT)

This multidisciplinary group identified commonly used outcome tools that were thought to be of value to the AAC community in terms of measuring services, achievements and personal development. A protocol for measuring these tools was outlined. Professor Pam Enderby was commissioned by the project group to evaluate the tools and appraise them against a protocol. This review has been discussed and agreed with the OM project group.  

Dithe Fisher, Janice Murray, Cathy Harris and Gillian Hazell provided additional editorial support.

‘The term AAC (Augmentative and Alternative Communication) covers a huge range of techniques which support or replace spoken communication. These include gesture, signing, symbols, word boards, communication boards and books, as well as Voice Output Communication Aids (VOCAs)’
The following section takes the reader through a number of issues that commonly recur when trying to choose a particular tool or measure. It defines outcome measurement, assessment and educational tools. To aid accessibility this has been compiled in the form of frequently asked questions. This section informs understanding of PART TWO of this document.
Frequently Asked Questions

1. Assessments, tools, outcome measures: are they different and why do we need them?

Sometimes these words are used interchangeably, and sometimes more specifically. In essence, most are used to guide intervention. Both formal and informal assessments help a professional (see footnote) to find the areas of strength in an individual and their areas of difficulty in order to inform their treatment plan.

**Formal (or standardised) assessments** are published following being tested carefully to establish their statistical strengths, which helps the professional to compare the results with others who have been assessed and also to be confident in the findings (aggregated data). It also ensures that the tester can monitor changes over time and be confident that those changes are real. Formal assessments are prescriptive in the way that they are carried out and frequently investigate, in some depth, a particular aspect such as: vocabulary, motor movement, eyesight, hearing, etc. Their strengths are in that they are based on strong theory and can identify or diagnose particular issues. Furthermore, they are sufficiently carefully structured to allow individuals to measure the change over time i.e. whether the person is improving in a particular area or having extra problems. However, formal assessments can be restrictive in that they have to be conducted in a specific way which can limit their usefulness with individuals who have unique combinations of difficulties, abilities and challenges. Some formal assessments can be used as an outcome measure but this will detect change on the specific item being tested alone.

Formal assessments:
- based on a particular theory
- prescriptive testing procedures
- psychometrically robust i.e. reliable and valid
- frequently have limited scope

Good for:
- identifying abilities and difficulties in certain areas
- comparing results with others with similar conditions
- monitoring change over time
- data can be aggregated

**Informal assessments** refer to procedures which have not been scientifically tested, or to formal assessments used in ways other than the published procedure. For example a professional may create specific tools to test an individual, may present only selected sections of a formal assessment or may modify how the assessment is administered. Informal assessments are often used by professionals who have experience in a particular area and wish to probe areas of strength and difficulty. These can assist the professional by providing additional information to inform their approach but they are not reliable, particularly for monitoring change.

Footnote: Assessments and Outcome measures can be used to monitor whether a person is responding to treatment and to review progress. Findings are only of value if the measures are stable, i.e. they can be used with a degree of reliability over time. For example, it would be of no value if the measure reflected the mood of the tester rather than the ability of the client. This could result in the client being determined as being worse or better, according to whether the tester was having a good day or not! See question 7 for explanation of validity, reliability and sensitivity.
In practice, informal and formal assessments/tests are often blended to ensure that the professional really gets to know the issues of particular importance.

Informal Assessments:
- depend upon the experience and expertise of the tester
- allow for more detailed investigation of certain areas
- not limited to certain areas
- data aggregated
- data cannot be relied on to monitor change over time

Good for:
- additional information on clients
- exploring barriers to progress
- assisting with the understanding of complex conditions

**Outcome measures** are also tools used to assess change in a person over time. The type of measure chosen would measure change in a specific aspect or aspects of a person’s life. Most outcome measurement tools enable multidisciplinary decisions to be made about treatment or methods of intervention. Formal outcome measures would follow a prescribed protocol for completion.

Selecting from the wide range of available measures can be challenging but may be informed by considering:

**Formal outcome measures:**
- prescriptive testing procedures
- psychometrically robust i.e. reliable and valid
- frequently have a broad scope of measurement across the domains of (i) clinical status, (ii) functional status, (iii) quality of life, (iv) satisfaction and (v) cost.

Good for:
- identifying abilities and difficulties in certain areas
- comparing results with others with similar conditions
- monitoring change over time
- data can be aggregated
2. Why do AAC services need more information? And do they need assessment or outcome measurement tools?

These questions have been answered by offering summary considerations that are relevant at a client level, service delivery level and at a service commissioning level. This consideration informed the suggestion that either an outcome measurement or assessment tool could provide that information. PART TWO of this document offers a summary of assessments and measures that may be most useful to the readers’ specific needs.

AAC services need information at a:

Client Level:
- to identify their strengths, difficulties and barriers; this informs intervention (by using assessment)
- their change over time (assessment and outcome measurement)
- the impact of their intervention (assessment and outcome measurement)

Service Level:
- to monitor service delivery (outcome measurement)
- strengths and weaknesses of service (outcome measurement)
- changes of service delivery over time, e.g. changing numbers and types of referrals, impact of changes to services (outcome measurement)
- research and audit (assessment and outcome measurement)
- Benchmarking (outcome measurement)

Purchaser/Commissioner level
- establish benefit of investment (data and outcome measurement)
- determine compliance with contract (data and outcome measurement)
- comparison of service providers (data and outcome measurement)
- National comparison (data and outcome measurement)
- research and audit (data, assessment and outcome measurement)

3. Why do we need outcome measures?

Outcome measures help us to judge the impact of interventions/services or treatments. Many different people have good reasons for wanting to know the effectiveness of an intervention.

- the client: will want to know if it has been worth the effort, cost, time etc;
- the healthcare provider/the person delivering the treatment: will want to know how effective their involvement has been, which interventions are more effective and for whom, and whether they have been as proficient as another provider.
- those who pay for the services, i.e. the commissioners: will want evidence that their investments have been justifiable.
Communication Matters: Outcome Measurement

4. What about monitoring progress?

It is important to be able to monitor progress during service interventions, e.g. 1 to 1 therapy or class based learning. The client, relative, professional and others involved need this information. It is important that progress is monitored broadly as well as specifically. Thus it may be important to assess whether an individual is capable of using an AAC device more efficiently but it is also important to monitor usage in a broad range of settings. This information can be collected in different ways both formally and informally and therefore it must be remembered that this information is to be used to adapt/inform interventions.

5. What is the difference between an assessment and an outcome measure?

Formal and informal assessments help the professional to identify the programme of care, intervention and its course and objectives. These should be informed and agreed with the person, their family and carers. However, the outcome of the intervention is likely to be broader ranging. For example, an assessment of speed of word finding using an AAC system may elicit information related to particular groups of words that are causing difficulty. This will help the clinician to tailor a particular approach to intervention. The outcome may be that the individual's word finding speed improves, their communication is more effective, they are able to integrate with their family more easily and are happier; this is a broader outcome than that which would be detected by reassessment of speed of word finding using an AAC system.

Some assessments can act as outcome measures but this is not always the case. For example, in the above scenario the clinician is likely to have wanted to improve more than just the speed and accurateness of word retrieval; their objectives of therapy would have been to improve communication effectiveness, encourage psychosocial integration and support the individual. Reassessing the speed of word finding may give some indication of an increased familiarity with the AAC system but successful communication is more than just speed of word finding. It will not give indications of other semantic or syntactic challenges and certainly will not indicate communication effectiveness and the broader integration of the individual.

6. What are the parameters to consider when choosing an outcome measure?

It is essential to ensure that an outcome measure is associated with the objectives of the intervention. Thus, if the intervention is aiming to improve the weight of an individual it would be inappropriate to measure their height! Furthermore, outcome measures need to be valid and reliable (see question 7) and if possible allow comparison between clients and professionals. You may wish to consider whether the outcome measure has theoretical underpinnings e.g. International Classification of Functioning or Communication Competence (See PART TWO). It is also desirable that an outcome measure is quick and easy to use and communicates the objectives of an intervention clearly to the client, relatives and commissioners.

7. Is it important to have a reliable, valid and sensitive measure? And what do these terms mean?

Any kind of assessment or outcome measurement must be developed in a way that gives the assessor accurate information about the performance of the individual.

Validity: there are different forms of validity but essentially they are measures to ensure that you are testing what you think you are testing. It gives you confidence that the test measures what you think it is measuring.

Reliability: this is usually established by looking at the consistency between two measures of the same
thing. It gives you confidence that the measure is stable, dependable and consistent and does not give you different results if the person has not changed.

**Sensitivity:** this ensures that the measure detects differences when there are differences. There is usually a trade-off between reliability and sensitivity as robust and reliable measures may not be able to detect small changes. Measures that can detect minor variations are often not as reliable.

**Factors affecting the choice of an appropriate outcome measure:**

The reason for measuring outcomes in a specific situation will influence the choice of outcome measure. If the aim is to compare service; the chosen measure should be one that is used by other services. If the aim is to provide information to commissioners of services; the measure should produce information in the form they require. If the aim is to review change over time; the chosen measure should capture a broad range of information that will be useful and reflect the information required. If the aim is to gather information for collaboration with other services the chosen measure should be compatible with the information they require and the tools they are using. Some measures may help with more than one of these issues.

Furthermore, some measures are more pertinent to issues associated with AAC use; whereas other measures are aimed at gathering information related to general disability or rehabilitation.

**8. What are the objectives of AAC services?**

Given that it is important to ensure that an outcome measure can elicit any change associated with the objectives of the intervention it is fundamental that those objectives are clearly identified. Thus before we consider whether an outcome measure is suitable or not we must identify the objectives of AAC services.

The objectives of services include:

- Improving the communicative effectiveness of the client in a range of settings.
- Improving the autonomy and integration of the individual.
- Having an impact on the mood and well-being of the client and their family.

Additionally, in some cases the objective might be to improve the underlying speech and language impairment e.g. a person with a severe speech disorder as well as cognitive disorder may benefit from AAC to develop cognitively and linguistically.
The information is as accurate as can be established at this time. Please contact Communication Matters (admin@communicationmatters.org.uk) to make any corrections. The following measures are not presented in any particular order of importance or relevance to AAC.
Informative Frameworks

Conceptual frameworks provide a structure which can help reflection when considering the choice of an outcome measure for a particular client group/s. The following may assist in reflecting the ambitions of service provision and thus the most appropriate approach to the selection of an outcome measure.

International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health, known more commonly as ICF (World Health Organisation 2001) is a classification of health and health-related domains. These domains are classified from body, (impairments), individual (activity restriction), and societal perspectives (participation) by means of two lists: a list of body functions and structures, and a list of domains of activity and participation. Since an individual's functioning and disability occur in a context, the ICF also includes a list of environmental factors.

http://www.who.int/classifications/icf/en/

Communication Competence proposed by Janice Light

Janice Light proposed a definition of communicative competence for individuals using AAC which has been broadly adopted. The proposed definition suggests that communicative competence is a relative and dynamic, interpersonal construct based on communication function, adequacy of communication, and sufficiency of knowledge, judgement, and skill in four interrelated areas: linguistic competence, operational competence, social competence, and strategic competence. Linguistic and operational competencies refer to knowledge and skills in the use of the tools of communication; social and strategic competencies reflect functional knowledge and judgement in interaction.

Light J. (1989) Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. Augmentative and Alternative Communication. Volume: 5, Issue: 2,

Framework for Outcome Measurement-AFROM

This approach developed by Kagan et al (2008) provides a conceptual guide to outcome assessment in aphasia situated within current thinking about health and disability. Whilst it was developed with particular reference to aphasia for capturing ‘the important but often elusive outcomes of interventions that focus on making a difference to every day life experience of individuals…’, the structure has been found to be valuable for a broad range of client groups with communication problems. Again this measure builds on the International Classification of Functioning Disability and Health (ICF) (World Health Organisation, 2001). The authors suggest that this platform can be used to identify areas to be considered when assessing outcome.

Information on Particular Measures

The measures reviewed in this section are those commonly referred to in the literature and most frequently used in AAC services in the UK.

Measures

The following list of measures is set out to provide a summary of the key considerations reviewed in PART ONE. In addition, a description of practical issues, e.g. time to complete, has been included. Costs have been omitted to maintain the currency of the document. Terms of reference used may vary, e.g. client, patient. The term quoted here reflects the language used within each publication.

1. Functional Independence Measure - FIM

Description and focus: FIM assesses physical and cognitive disability. The scale focuses on the ‘ burden of care ’ – that is, the level of disability indicating the burden of care.

The FIM is an 18-item, seven level ordinal scale.

It is one of the most commonly used functional assessment tools. Items are scored on the level of assistance required for an individual to perform activities of daily living. The scale includes 18 items, of which 13 are physical domains based on the Barthel Index (see footnote) and 5 are cognition items.

Each item is scored from 1 to 7 based on level of independence, where 1 represents total dependence and 7 indicates complete independence. Possible scores range from 18 to 126, with higher scores indicating more independence.

Alternatively, 13 physical items could be scored separately from the 5 cognitive items.

<table>
<thead>
<tr>
<th>Motor Items</th>
<th>Cognitive Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating</td>
<td>Comprehension</td>
</tr>
<tr>
<td>Grooming</td>
<td>Expression</td>
</tr>
<tr>
<td>Bathing</td>
<td>Problem solving</td>
</tr>
<tr>
<td>Dressing uppers</td>
<td>Social interaction</td>
</tr>
<tr>
<td>Dressing lowers</td>
<td>Memory</td>
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<tr>
<td>Bladder</td>
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<tr>
<td>Bowel</td>
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<tr>
<td>Toileting</td>
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<tr>
<td>Transfer bed/chair/wheelchair</td>
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<tr>
<td>Toilet transfers</td>
<td></td>
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<tr>
<td>Tub/shower</td>
<td></td>
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<tr>
<td>Walk/wheelchair</td>
<td></td>
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<tr>
<td>Stairs</td>
<td></td>
</tr>
</tbody>
</table>

Outcome Measure or Assessment: Outcome Measure

Who can complete: any trained health care practitioner. Can be administered by a physician, nurse, therapist or layperson.
Training required: Clinicians must be trained before they can use. Training can take one hour.

How Long to Complete: 30 minutes to score each patient.

User involvement: Patient is required to comply with the undertaking certain tasks and their views are sought but professional undertakes the scoring.

Population covered: The measure has been used with a range of populations. Mostly older people with acquired difficulties.

Psychometric properties: FIM has been tested in a variety of settings and validity and reliability are strong. Generally ‘recognized as the rehabilitation industry’s most reliable, valid, and responsive functional assessment tool’ (Stineman et al., 1996).

Can data be aggregated: Yes - mostly used for this purpose.

Appropriateness to AAC: Potentially, yes - Whilst FIM incorporates items of expression and comprehension these are at a superficial level. FIM does not include reading writing and intelligibility.


Footnote: The Barthel scale or Barthel ADL index is an ordinal scale used to measure performance in activities of daily living (ADL). It does not refer to communication ability. Each performance item is rated on this scale with a given number of points assigned to each level or ranking. It uses ten variables describing ADL and mobility. A higher number is associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital. The amount of time and physical assistance required to perform each item are used in determining the assigned value of each item.
2. The Functional Assessment Measure - FAM

**Description and focus:** The Functional Assessment Measure (FAM) includes FIM items and adds 12 extra items, mainly covering cognition, such as community integration, emotional status, orientation, attention, reading and writing skills, and employability.

**Outcome Measure or Assessment:** Outcome Measure

**Who can complete:** Scoring is done by a multi-disciplinary team member. The subject is scored on what the patient can actually do on a day-to-day basis, not on what they could do.

**Training required:** Clinicians must be trained before they can use. Training can take one hour.

**How Long to Complete:** 35 minutes to 1 hour

**User involvement:** Patient is required to comply with the undertaking certain tasks and their views are sought but the professional undertakes the scoring.

**Population covered:** As FIM. ‘This scale was originally intended for patients with brain injury, but is in fact useful in all rehabilitation settings.’ Commonly used in rehabilitation units.

**Psychometric properties:** Strong reliability and validity

**Can data be aggregated:** Yes—mostly used for this purpose.

**Appropriateness for AAC:** FIM-FAM combined is a candidate for consideration. However, there is very little user involvement and limited communication specific items make it insensitive to change in functional communication.


Developer: Jerry Wright, MS, Clinical Research Manager, Rehabilitation Research Center, Santa Clara Valley Medical Center.

For more information please visit The Center for Outcome Measurement in Brain Injury (FAM Training & Testing is also available here) or contact Jerry Wright at jerry.wright@hhs.sccgov.org
3. Quality of life scale - QOLS

**Description and focus:** There are several different measures with the same name. Quality of life (QOL) measures have become a vital and often required part of health outcomes appraisal. For populations with chronic disease, measurement of QOL provides a meaningful way to determine the impact of health care when cure is not possible. Over the past 20 years, hundreds of instruments have been developed that purport to measure QOL. With few exceptions, these instruments measure causal indicators of QOL rather than QOL itself.

Health care professionals need to be clear about the conceptual definition of QOL and not to confound it with functional status, symptoms, disease processes, or treatment side-effects.

**Example of one measure:** The QOLS was originally a 15-item instrument that measured five conceptual domains of quality of life: material and physical well-being, relationships with other people, social, community and civic activities, personal development and fulfillment, and recreation this has been expanded to include independence. The original work on the QOLS was undertaken in the United States in the mid-1970's.

**Outcome Measure or Assessment:** can be used as both

**Who can complete:** service user or general population

**Training required:** none

**How Long to Complete:** not stated—variable—however long the user wants to consider items

**User involvement:** Central

**Population covered:** Any, but not suitable for young children

**Psychometric properties:** not established

**Can data be aggregated:** Yes

**Appropriateness for AAC:** possibly for early years but lacks essential detail.

4. Quality-Of-Life Inventory - QOLI

Description and focus: The QOLI assessment yields an overall score and a profile of problems and strengths in 16 areas of life such as love, work and play. The QOLI test is a measure of positive psychology and positive mental health. It claims to assess the positive health, well being and quality of life of clients of 17 years of age and over. Most data/information on this inventory is associated with clients using mental health services.

32 items with 3-point rating scale for importance, and 6-point rating scale for satisfaction

Incorporates scales:

- Health
- Self-Esteem
- Goals and Values
- Money
- Work
- Play
- Learning
- Creativity
- Helping
- Love
- Friends
- Children
- Relatives
- Home
- Neighbourhood
- Community

Outcome Measure or Assessment: Assessment

Who can complete: Self completion

Training required: None

How Long to Complete: 'brief'

User involvement: self completion

Population covered: any over 17 years of age, also a child version

Psychometric properties: normative data gained from the US

Can data be aggregated: not appropriate

Appropriateness for AAC: perhaps for some individuals (developed and validated within the US)

5. Goal Attainment Scaling - GAS

**Description and focus:** This tool is designed to be used in situations where specific goals are set jointly between the worker and client as part of a case management process and within a particular time frame.

Individualised criterion-referenced measure to quantify achievement of specific goals of treatment, expressed as behavioural objectives. Goals are set by professionals with patients and carers, and have a 5-point ordinal scale of attainment with 2 levels above and 2 below the principle goal.

Can be organised using ICF or Light criteria.

**Outcome Measure or Assessment:** Outcome Measure

**Who can complete:** Professional with service users

**Training required:** ‘staff need training prior to use’

**How Long to Complete:** variable

**User involvement:** it is recommended that goals are identified in discussion between the professional and patient

**Population covered:** All

**Psychometric properties:** ‘Despite numerous studies, the reliability and validity of GAS remain questionable.‘

1. ‘Comparisons showed that GAS, because of its idiosyncratic nature, measures different constructs from those measured by some related instruments. Low concurrent validity was found. All included studies reported good sensitivity to change.

**Can data be aggregated:** No

** Appropriateness to AAC:** appropriate on an individual basis--- has been recommended for AAC see below(1)


6. The Short Form Health Survey (36) - SF 36

**Description and focus:** commonly used in health economics and to assess quality adjusted life years. This aims to capture practical, reliable, and valid information about functional health and well-being from the patient's point of view. It is also used in generic health surveys because these surveys can be used across age, disease, and treatment group, and are appropriate for a wide variety of applications. Conversely, disease-specific health surveys are focused on a particular condition or disease.

The eight sections are:

- vitality
- physical functioning
- bodily pain
- general health perceptions
- physical role functioning
- emotional role functioning
- social role functioning
- mental health

**Outcome Measure or Assessment:** primarily used in surveys of health in specific populations. Has been used in studies of outcome

**Who can complete:** self completion

**Training required:** none for undertaking. Training required for analysis of results

**How Long to Complete:** less than 10 minutes

**User involvement:** user self report

**Population covered:** over 18; adapted scales for many conditions e.g. stroke, cardiovascular disease and arthritis.

**Psychometric properties:** Strong. Scores are calibrated so that 50 is the average score or norm. This norm-based score allows comparison among the surveys. More than 17,000 studies published in the past 20 years.

**Can data be aggregated:** yes

** Appropriateness to AAC:** little information specifically appropriate to identify the value of use of assistive devices

7. Therapy Outcome Measure - TOM

**Description and focus:** The Therapy Outcome Measure is based on the World Health Organisation's International Classification of Functioning (ICF). It is a professional-rated rehabilitation outcome measure and contains four dimensions: Impairment (degree of severity of disorder e.g. the severity of dysarthria); Activity restriction (e.g. Degree of limitation in communication); level of Social participation; and Wellbeing (effect on emotion/level of distress), with each dimension scored on an 11-point ordinal scale (0 to 5, including half-points). Lower scores indicate more severity/difficulty. Operational definitions of these ratings are given for 26 conditions including:

- speech and language impairment,
- phonological disorder,
- dysarthria,
- dysfluency,
- dysphagia,
- dysphasia,
- dystonia,
- learning difficulties,
- cognitive impairment,
- cerebral palsy,
- stroke,
- neurological disorders,
- multifactorial conditions,
- complex and multiple difficulty

**Outcome Measure or Assessment:** outcome measure

**Who can complete:** professional/health care professional involved in care of patient/client

**Training required:** training is required—can be undertaken by staff themselves using manual. Recommended that individual becomes familiar with the manual gains experience on 10 patients

**How Long to Complete:** 3-5 minutes

**User involvement:** embedded

**Population covered:** all

**Psychometric properties:** Strong validity and reliability established in the UK

**Can data be aggregated:** yes

** Appropriateness for AAC:** yes – specific mention of AAC


8. **Australian Therapy Outcome Measure - AusTOM**

**Description and focus:** based on The Therapy Outcome Measure (see above) which incorporates the International Classification of Functioning (World Health Organisation) covering impairment, activity restriction, psychosocial limitation and well-being-11 point ordinal scale. Modified for use in Australian context.

There are separate scales for occupational therapy and physiotherapy and speech and language therapy. There are six speech pathology scales, nine physiotherapy scales, and 11 occupational therapy scales in the AusTOMs. A clinician chooses the relevant scale(s) for the client (based on the goals of therapy) and makes a rating across all domains for each scale.

**Outcome Measure or Assessment:** Outcome Measure

**Who can complete:** Professional treating the patient

**Training required:** Recommended that individual becomes familiar with the manual gains experience on 10 patients

**How Long to Complete:** 3 to 5 minutes

**User involvement:** embedded

**Population covered:** all clients/patients receiving therapy/rehabilitation

**Psychometric properties:** validity and reliability tested in Australia only

**Can data be aggregated:** Yes

**Appropriateness to AAC:** Yes – potentially strong candidate


9. Self Image Profile for Adults- SIP-Ad:
   SIP A for Adolescents aged 12 to 16
   SIP C for children aged 7 to 11

Description and focus: 30 items to determine self image and self-esteem. The SIP-Adult consists of 32 items rated by the respondent in terms of both how they think of themselves and how they would like to be. The SIP-Adult provides a visual display of self image, enabling the individual, as they complete it, to reveal to him/herself, as well as to the clinician, ways they construe themselves.

The SIP-Adult also provides a measure of Self Esteem, which is calculated by the discrepancy between ratings of 'How I am' and 'How I would like to be'.

Outcome Measure or Assessment: Assessment

Who can complete: Service User

Training required: None

How Long to Complete: Variable --- as long as the user would wish.

User involvement: self complete by user. ‘fosters collaboration between respondent and clinician, which befits its employment in clinical practice’

Population covered: all-- also suitable for people without pathology.

Psychometric properties: strong validity determined on a study of more than 1000 adults in the UK. No studies of test retest reliability.

Can data be aggregated: not appropriate

Appropriateness to AAC: yes for self-esteem

10. Wellbeing Evaluation Scale - WES

**Description and focus:** Informed by an evidence-based theoretical framework the WES was developed with a reading age of 12 years, and has both long (47 item) and short (19 item) questionnaires. Respondents rate themselves against statements on a 5-point Likert scale.

The 47 item Long Form provides a measure of subjective, behavioural and contextual dimensions of well-being across 6 structural properties of well-being:

- Integrity of self
- Integrity of others
- Belonging
- Agency
- Enrichment
- Security

Responses are collated and provide a profile of well-being across all 6 domains in addition to population percentages.

The 19 item Short Form provides an average wellbeing score and population percentages. Can be used in all health and social care settings.

**Outcome Measure or Assessment:** Primarily an assessment --- could be used as outcome measure

**Who can complete:** Service User

**Training required:** None -- interpretation of results would be assisted by training

**How Long to Complete:** Variable --- as long as the user would wish.

**User involvement:** self complete by user

**Population covered:** over 12 years of age -- also suitable for people without pathology.

**Psychometric properties:** information not available

**Can data be aggregated:** not recommended

**Appropriateness to AAC:** yes for well-being

11. Canadian Occupational Performance Measure - COPM

Description and focus: The Canadian Occupational Performance Measure (COPM) is an individualized outcome measure designed for use by occupational professionals. The measure is designed to detect change in a client’s self-perception of occupational performance over time. Its focus is on self-care, productivity and leisure. Using a semi-structured interview, the COPM is a five step process which measures individual, client-identified problem areas in daily function. Two scores, for performance and satisfaction with performance are obtained.

Translated into 20 languages.

Outcome Measure or Assessment: Outcome Measure

Who can complete: primarily used by occupational professionals in discussion with clients

Training required: recommended: DVD available

How Long to Complete: reported to be 20 to 40 minutes

User involvement: semi-structured interview format and structured scoring method.

Population covered: all occupational therapy clients over the age of eight.

Psychometric properties: structured scoring method. Considerable research has been undertaken demonstrating support for the reliability and validity of the COPM.

Can data be aggregated: methods of amalgamation have been used at a surface level

Appropriateness for AAC: yes – functional participation focus

12. The Communication Matrix

Description and focus: The Communication Matrix is an assessment tool designed to pinpoint exactly how an individual is communicating and to provide a framework for determining logical communication goals. It was first published in 1990 and was revised in 1996 and 2004 by Charity Rowland of Oregon Health & Science University. It was designed primarily for speech-language pathologists and educators to document the expressive communication skills of children who have severe or multiple disabilities, including children with sensory, motor and cognitive impairments.

It assesses seven levels of communication:

1. Level I. Pre-Intentional Behavior
2. Level II. Intentional Behavior
3. Level III. Unconventional Communication
4. Level IV. Conventional Communication
5. Level V. Concrete Symbols
6. Level VI. Abstract Symbols
7. Level VII. Language

Outcome Measure or Assessment: Assessment (due to lack of psychometric information)

Who can complete: parents-close relative. Frequently used by speech and language professionals

Training required: none required

How Long to Complete: 10 minutes-one hour

User involvement: developed to be used by parents of children—can be used for adults with severe communication deficits.

Population covered: persons of all ages with severe communication deficits.

Psychometric properties: no information available

Can data be aggregated: not appropriate

Appropriateness for AAC: Yes – strong candidate for pre intentional/intentional communicators

13. Social Networks: a Communication Inventory for Individuals with Complex Communication Needs and Their Communication Partners

Description and focus: Designed to help professionals work with family members and individuals with complex communication needs to determine the most appropriate technologies and communication strategies for communication with partners in various contexts.

Outcome Measure or Assessment: assessment and treatment guide

Who can complete: Main carer or health care professional

Training required: Required/DVD available

How Long to Complete: not specified can be lengthy if required

User involvement: user centred

Population covered: from three years upwards

Psychometric properties: not assessed

Can data be aggregated: not appropriate

Appropriateness for AAC: yes - designed specifically for AAC


Sarah W. Blackstone, Ph.D. CCC-SP, Augmentative Communication Inc. Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC) sarahblack@aol.com www.augcominc.com
14. The Outcomes Star

Description and focus: The Outcomes Star™ is a suite of tools for supporting and measuring change when working with vulnerable people. It was developed by Triangle Consulting and published by the London Housing Foundation in December 2006. The Outcomes Star™ both measures and supports progress for service users towards self-reliance or other goals. The Stars are designed to be completed collaboratively as an integral part of key work. They are sector wide tools - different versions of the Star include homelessness, mental health and young people. All versions consist of a number of scales based on an explicit model of change. Used by many voluntary agencies.

It is based on ten outcome areas chosen as appropriate to the population. Each outcome area has a ten-point scale. The behaviour and attitudes associated with each point on the scale are described in the ladders and detailed scales.

Outcome Measure or Assessment: an informal progress measure and therapy tool.

Who can complete: practitioner and the service user together.

Training required: training is available online for free – stated that this improves consistency of scoring.

How Long to Complete: variable

User involvement: integral to collecting data

Population covered: stars have been developed for a range of conditions. The following is a list of the versions currently available:

- Alcohol Star™
- Community Star™
- Empowerment Star™ - for domestic violence services
- Family Star™
- Homelessness Star™
- Mental Health Recovery Star™
- Music Therapy Star™
- Older Person’s Star™
- Teen Star™
- Well-being Star™
- Work Star™
- In addition the following are currently in development:
  - Sexual Health Star™
  - Spectrum Star™ - for autism and Aspergers
  - Life Star™ - for learning disability

Psychometric properties: concern has been expressed regarding the reliability and validity. (www.homelessoutcomes.org.uk)

Can data be aggregated: caution as scoring has been found to vary.

Appropriateness for AAC: yes – but an adapted scale would need to be developed.

http://www.outcomesstar.org.uk/who-we-are/
15. Psychosocial Impact of Assistive Devices Scale - PIADS

**Description and focus:** PIADS© is a 26-item, self-rating questionnaire that is designed to measure a person's perceptions of how assistive devices affect their quality of life. The PIADS© describes user experiences along three dimensions:

- Competence: Measures feelings of competence and usefulness.
- Adaptability: Signifies a willingness to try new things.
- Self-esteem: Indicates feelings of emotional wellbeing and happiness

The user rates each item using a 7-point scale that ranges from -3 (maximum negative impact) to +3 (maximum positive impact). The mid-point, zero, indicates no impact or no perceived change as a result of using the device. PIADS© research projects funded by The Canadian Institutes of Health Research (CIHR), The Canadian Stroke Network (CSN), and the National Institute for Disability and Rehabilitation Research (NIDRR) are underway.

Subscales of the PIADS:

- Adaptability (reflecting inclination or motivation to participate socially and take risks; ICF Participation)
- Competence (reflecting perceived functional capability, independence and performance; ICF Activity)
- Self-esteem (reflecting self-confidence, self-esteem, and emotional well being).

**Outcome Measure or Assessment:** outcome measure

**Who can complete:** service user led— can be filled in by proxy

**Training required:** CD available

**How Long to Complete:** variable

**User involvement:** Central

**Population covered:** any user of assistive devices

**Psychometric properties:** ‘Research has established that the instrument has good internal consistency, test-retest reliability, and construct validity. It is a responsive measure and sensitive to important variables such as the user’s clinical condition, device stigma, and functional features of the device. It has been shown to accurately reflect the self-described experiences of people who use assistive devices.’ (Author’s comment)

**Can data be aggregated:** No

**Appropriateness for AAC:** Yes – a strong candidate

Webcast on assistive technology outcome measures:

http://piads.ca/9/webcast1.2.htm
Email: jjutai@uottawa.ca

16. Circles of Communication Partners - CCP

**Description and focus:** The Circles of Communication Partners (CCP) is a paradigm adapted from Marsha Forest’s Circle of Friends (Forest & Snow). It is being used in surveys to collect information about the communication partners of individuals who use AAC. ‘The CCP profile for augmented communicators is useful clinically because it identifies the configuration of partners for individuals who use AAC across communication contexts’ (Blackstone, 1999). The augmented communicator is at the centre. Emanating outward are five circles, which represent different types of partners (and relationships) as described below:

The inner circle contains the augmented communicator’s life partners.
- Good friends are represented in the second circle.
- The third circle is comprised of favourite neighbours, colleagues and acquaintances.
- The fourth circle includes people who are paid to interact with the augmented communicator.
- The outer circle is the universe of unfamiliar partners.

**Outcome Measure or Assessment:** not developed as either but could be used in assessment and treatment.

**Who can complete:** anyone working with individual AAC user.

**Training required:** knowledge of the theory is required

**How Long to Complete:** not specified-- can be very short or in-depth.

**User involvement:** any level of involvement- can be self completion.

**Population covered:** any AAC user

**Psychometric properties:** not specified-- we have not found any research related to reliability or validity.

**Can data be aggregated:** not appropriate

**Appropriateness for AAC:** yes - developed entirely for use with AAC


17. Communication Competencies (Janice Light)

**Description and focus:** The communication competencies are a list of key skills that an individual who uses AAC needs to develop in order to become a competent communicator. They were developed by Janice Light, an American speech and language professional. These include: Linguistic competence, Operational competence, Social competence, and Strategic competence. Linguistic and operational competencies refer to knowledge and skills in the use of the tools of communication; social and strategic competencies reflect functional knowledge and judgement in interaction.

In 2007 this was extended to include psychosocial and environmental issues.

“Communication competence suggests an adequate level of communication skills to function within the environment; it does not imply total mastery of the art of communication” (Light, J, 1998)

**Outcome Measure or Assessment:** used to inform goals and measure progress with an individual

**Who can complete:** speech and language therapists or any knowledgeable AAC practitioner.

**Training required:** training required in the underlying theory and principles

**How Long to Complete:** not specified

**User involvement:** central ‘the approach can facilitate user understanding goal setting’.

**Population covered:** all AAC users and communication impaired individuals.

**Psychometric properties:** not determined

**Can data be aggregated:** not appropriate

**Appropriateness for AAC:** yes – appropriate to use to inform application of outcome measurement tool

Light J. Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. Augmentative and Alternative Communication (1989) Volume: 5, Issue: 2, Publisher: Informa UK Ltd UK, Pages: 137-144.

18. Language Activity Monitor - LAM

**Description and focus:** The collection and analysis of performance data for automated performance monitoring tools to use in clinical practice. Language activity monitoring (LAM) is the systematic data collection of the actual language activity of an individual who relies on AAC. The LAM records the time and content of language events (the generation of one or more letters or words.) A logging protocol suitable for clinical application has been in use since late 1998. The logged data is uploaded periodically to a computer for editing, analysis, and the generation of a summary measure report.

LAM tools (hard and software) fall into three areas. The LAM records the language data. The LAM Edit computer program provides for the semi-automation of the process of preparing the data for analysis. Analysis tools look at the data and report specific information.

The LAM function creates a record of the time of day and content of each language event, the generation of one or more letters or words. Non-language events, such as device operation functions, also can be recorded. Standardization of the reporting protocol has been proposed to assure compatibility among various recording, editing, and analysis features and tools (Hill & Romich 1999a). LAM can record language data in the natural environment over many days as readily as in controlled sessions.

**Outcome Measure or Assessment:** Neither - LAM is a recording device. The data can be used for assessment or outcome measurement.

**Who can complete:** the hard and software automatically record information.

**Training required:** need special software and knowledge of analysis.

**How Long to Complete:** none, data saved automatically

**User involvement:** clients and conversational partner should be informed that activity is being monitored

**Population covered:** any AAC user with AAC device that can be integrated with LAM

**Psychometric properties:** not applicable - measure of operational and linguistic performance. As it only records the users’ output it can not measure social and strategic competence and performance.

**Can data be aggregated:** yes activity data can be aggregated

**Appropriateness for AAC:** Appropriate. However concern has been expressed regarding the possible invasion of privacy and it is important to stress that informed permission of the parties involved must be sought.

Edyburn, D. L. (1999). I can see the technology is being used, but is it effective? 17th Annual Closing the Gap Conference. Minneapolis, MN. October 21-23.


19. East Kent Outcome System - EKOS

Description and focus: This is an outcome collection system which is embedded in an approach to general note keeping, service planning and closely linked to intervention. Following assessment, goals are agreed with the patient/client and at the end of treatment the goals are reviewed and noted as having being met fully, mostly, partially or not at all. A good outcome is considered to be when 70 per cent or more of the goals are achieved.

Outcome Measure or Assessment: identified as both

Who can complete: professional in discussion with patient

Training required: recommended

How Long to Complete: not defined

User involvement: goals are identified and agreed with the service user----it is recommended that the level of achievement i.e. whether the goals have been met is also discussed with the user.

Population covered: people of all ages who require rehabilitation/ therapy involving AAC

Psychometric properties: not tested - this is fundamentally a note keeping system. A study has found that one of the major problems with this is that data is not always recorded.

Can data be aggregated: some data can be aggregated

Appropriateness for AAC: yes - potentially a strong candidate

Johnson, M & Elias, A (2010 revised editions) East Kent Outcome System for Speech and Language Therapy. East Kent Coastal Primary Care Trust.


20. Malcomess Care Aims

Description and focus: a philosophy of care known as the Malcomess Care Aims Model was developed by Kate Malcomess whilst she was working in the Croydon Speech and Language Therapy Service in South London. The model was designed to support practitioners to demonstrate evidence-based practice through systematic reflection. Care Aims gives consideration to lowering clinical risk, and looks at outcomes in a range of intervention areas including assessment, resolving difficulties, supporting through changing the environment and preventative work.

A5 laminated quick reference cards are available with the decision-making flowchart on one side and the Care Aim definitions on the reverse. Practitioners find them helpful as an aide memoir.

Outcome Measure or Assessment: a data management tool that may draw from outcome measurement and assessment data

Who can complete: clinical lead /professional

Training required: recommended

How Long to Complete: no information

User involvement: recommended

Population covered: all receiving speech and language therapy.

Psychometric properties: no information

Can data be aggregated: some

Appropriateness for AAC: Yes


21. Early Years Foundation Stage Profile

Description and focus: The Early Years Foundation Stage (EYFS) is a comprehensive statutory framework that sets the standards for the learning, development and care of children from birth to five in England and Wales. It is recommended that providers use the EYFS to ensure that whatever setting parents choose, they can be confident their child will receive a quality experience that supports their care, learning and development.

The primary purpose of the EYFS profile is to provide year 1* professionals with reliable and accurate information about each child’s level of development as they reach the end of the EYFS, enabling the professional to plan an effective, responsive and appropriate curriculum that will meet all children’s needs. (* year 1 refers to children of 6 years of age in England).

The EYFS profile sums up and describes each child’s development and learning achievements. It is based on ongoing observation and assessment in six areas of learning and development, namely:

- personal, social and emotional development
- communication, language and literacy
- problem solving, reasoning and numeracy
- knowledge and understanding of the world
- physical development
- creative development.

There are a set of 13 assessment scales, each of which has nine scale points.

The manual states:

‘where any item in the EYFS profile scales contains the word ‘talks’, children can use their established or preferred mode of communication. Practitioners will be alert to children demonstrating their attainment in a variety of ways, including eye pointing, use of symbols or signs. Any adaptations children use to carry out their activities, such as mobility aids, magnification, adapted ICT and equipment, should be employed so that practitioners come to know children at their most capable.’

Outcome Measure or Assessment: Assessment/guide

Who can complete: Well-qualified and effective practitioners can be identified by local authorities to form a team of moderators:

Training required: Annual moderation training required.

How Long to Complete: Not specified

User involvement: not applicable

Population covered: early years

Psychometric properties: not established

Can data be aggregated: Yes

Appropriateness for AAC: possibly for early years but lacks essential detail
22. Award Scheme Development and Accreditation Network - ASDAN

**Description and focus:** ASDAN is a charitable social enterprise with awarding body status, providing courses to more than 6,000 UK and international schools, colleges, youth centres and training providers. ASDAN's programmes and qualifications offer flexible ways to accredit skills for learning, skills for employment and skills for life. ASDAN rewards learners’ success in a range of skills and settings from Entry Level to University Entrance. It grew out of research work at the University of the West of England in the 1980s and was formally established as an educational charity in 1991.

It provides educational opportunities for young people, helping learners to develop their personal and social attributes through its award programmes and qualifications.

**Outcome Measure or Assessment:** neither – it offers opportunities and qualifications

**Who can complete:** registered trainers

**Training required:** leaders need training

**How Long to Complete:** not applicable

**User involvement:** full involvement

**Population covered:** ‘Young people’

**Psychometric properties:** qualifications have established criteria

**Can data be aggregated:** at a superficial level

**Appropriateness for AAC:** possible opportunities for AAC uses--but not as an outcome measure or assessment
23. City and Guilds - Augmentative and Alternative Communication

The City and Guilds Award and Certificate in Augmentative and Alternative Communication qualifications are designed to be wide ranging qualifications that allow learners to develop effective communication. They are designed to be taught or facilitated by a variety of professionals and carers including professionals, speech and language therapists and physiotherapists.

**Outcome Measure or Assessment:** achievement of a qualification could be seen as an outcome measure

**Who can complete:** AAC user must register to undertake a City and Guilds award. These qualifications are delivered at the centres which must be approved to deliver them and are only approved if they have access to necessary AAC resources to meet the needs of the learner.

**Training required:** professionals need to be trained and accredited to guide and teach City and Guilds awards.

**How Long to Complete:** these awards can be done at various levels and take 3 to 4 years

**User involvement:** Central

**Population covered:** Any—not suitable for young children

**Psychometric properties:** the City and Guilds accreditation establishes criteria/levels

**Can data be aggregated:** possibly not appropriate

**Appropriateness for AAC:** entirely appropriate
## Communication Matters: Outcome Measurement

### Summary

<table>
<thead>
<tr>
<th>Tool / Measure</th>
<th>Focus</th>
<th>Psychometric properties</th>
<th>Framework</th>
<th>Appropriate as OM in AAC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Independence Measure-FIM</td>
<td>General outcome measure for overall function of client</td>
<td>Strong</td>
<td>None specific</td>
<td>Not</td>
</tr>
<tr>
<td>Functional assessment measure- FAM</td>
<td>General outcome measure for overall function of clients</td>
<td>Strong</td>
<td>None specific</td>
<td>Not-limited focus on communication</td>
</tr>
<tr>
<td>SF36</td>
<td>General outcome measure for overall function of client</td>
<td>Strong</td>
<td>None specific</td>
<td>Not</td>
</tr>
<tr>
<td>Quality of Life Scale</td>
<td>General outcome measure for overall function of client</td>
<td>Weak</td>
<td>None specific</td>
<td>Yes- but one aspect only</td>
</tr>
<tr>
<td>Quality of Life Inventory</td>
<td>General outcome measure for overall function of client</td>
<td>None specific</td>
<td>Yes- but one aspect only</td>
<td></td>
</tr>
<tr>
<td>Goal Attainment Scaling</td>
<td>General outcome measure for overall function of client</td>
<td>Weak</td>
<td>None specific</td>
<td>Yes</td>
</tr>
<tr>
<td>Therapy Outcome Measures</td>
<td>Can be specifically for AAC/communication impairment</td>
<td>Strong-for UK</td>
<td>ICF</td>
<td>Yes</td>
</tr>
<tr>
<td>Australian Therapy Outcome Measures</td>
<td>Can be specifically for AAC/communication impairment</td>
<td>Strong for Australia</td>
<td>ICF</td>
<td>Yes-- but psychometrics established in Australia</td>
</tr>
<tr>
<td>Self Image Profile</td>
<td>Relevant for one aspect</td>
<td>Strong validity-UK</td>
<td>None specific-QOL</td>
<td>Yes- but one aspect only</td>
</tr>
<tr>
<td>Wellbeing Evaluation Scale</td>
<td>Measures the general well-being</td>
<td>No information available</td>
<td>QOL</td>
<td>Yes- but one aspect only</td>
</tr>
<tr>
<td>Canadian Occupational Performance Measure</td>
<td>Primary used by occupational professionals-could be used for AAC</td>
<td>Strong validity</td>
<td>None specific</td>
<td>Yes</td>
</tr>
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## Communication Matters: Outcome Measurement

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</thead>
<tbody>
<tr>
<td>The Communication Matrix</td>
<td>To be used by parents of those with severe communication problems</td>
<td>No information available</td>
<td>Can inform activity &amp; participation aspects - ICF &amp; the Light Framework</td>
<td>Yes</td>
</tr>
<tr>
<td>Social Networks (Blackstone)</td>
<td>Assessment to determine best communications strategy</td>
<td>No information available</td>
<td>Can inform activity &amp; participation aspects - ICF &amp; the Light framework</td>
<td>Yes - but one aspect only</td>
</tr>
<tr>
<td>The Outcomes Star</td>
<td>Progress measure and therapy tool</td>
<td>Concern has been expressed regarding the reliability of liberty</td>
<td>None specific</td>
<td>Yes</td>
</tr>
<tr>
<td>Psychosocial Impact of Assistive Devices Scale</td>
<td>Assesses the satisfaction of the client with assistive device</td>
<td>Strong – tested with some kind groups in Canada</td>
<td>Complies with the participation scale of the ICF</td>
<td>Yes</td>
</tr>
<tr>
<td>Circle of communication partners (Blackstone)</td>
<td>Determines the range of communication partners of AAC users</td>
<td>Not determined</td>
<td>Complies with the participation scale of the ICF</td>
<td>Yes</td>
</tr>
<tr>
<td>Janice Light communication competencies</td>
<td>Used to inform goals of treatment</td>
<td>Not determined</td>
<td>Complies with the activity restriction and participation scale of the ICF</td>
<td>Yes</td>
</tr>
<tr>
<td>Language Activity Monitor (on PRI devices)</td>
<td>Method/device to determine amount of usage of AAC device</td>
<td>Not determined</td>
<td>Complies with the activity restriction scale of the ICF</td>
<td>Yes</td>
</tr>
<tr>
<td>Tool / Measure</td>
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<td>----------------------------------------</td>
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</tr>
<tr>
<td>East Kent Outcome Scales</td>
<td>Outcome measurement embedded within general management system</td>
<td>Not determined</td>
<td>Could reflect any framework</td>
<td>Yes</td>
</tr>
<tr>
<td>Malcomess Care Aims</td>
<td>Outcome measurement embedded within general management system</td>
<td>Not determined</td>
<td>Could reflect any framework</td>
<td>Yes</td>
</tr>
<tr>
<td>Early years Foundation Stage Profile</td>
<td>Child development measure 0-5 years</td>
<td>Not established</td>
<td>General</td>
<td>Includes gathering data on general development of speech and language</td>
</tr>
<tr>
<td>Award Scheme Development and Accredit Network</td>
<td>Awards programme and qualification scheme</td>
<td>Criteria established-- no information on psychometric properties</td>
<td>Not applicable</td>
<td>Yes</td>
</tr>
<tr>
<td>City and Guilds</td>
<td>Awards programme and qualification scheme</td>
<td>Criteria established/ replicable</td>
<td>Not applicable</td>
<td>Yes- Specific for AAC</td>
</tr>
</tbody>
</table>