

Approaches to communication assessment with children and adults with profound intellectual and multiple disabilities

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Abstract

Communication assessment of people with profound intellectual and multiple disabilities (PIMD) has seldom been investigated. Here, we explore approaches and decision making in undertaking communication assessments in this group of people. A questionnaire was sent to UK practitioners. The questionnaire elicited information about assessment approaches used and rationales for assessment choices. Fifty-five speech and language therapists (SLTs) responded. Findings revealed that the Preverbal Communication Schedule, the Affective Communication Assessment and the Checklist of Communication Competence were the most frequently used published assessments. Both published and unpublished assessments were often used. Rationales for assessment choice related to assessment utility, sensitivity to detail and change and their applicability to people with PIMD. Underpinning evidence for assessments was seldom mentioned demonstrating the need for more empirical support for assessments used. Variability in practice and the eclectic use of a range of assessments was evident, underpinned by practice-focused evidence based on tacit knowledge.

1 | INTRODUCTION

People of all ages with profound intellectual and multiple disabilities (PIMD) experience significant challenges in relation to communication, with limited comprehension of speech and communication at pre-symbolic or proto-symbolic levels (Bellamy, Croot, Bush, Berry, & Smith, 2010; Iacono, West, Bloomberg, & Johnson, 2009; Maes, Lambrechts, Hostyn, & Petry, 2007). Accordingly, assessment of their communication needs to be addressed in some detail during these early developmental stages. Brady et al. (2018) clearly identify the “void” in options for detailed assessment of these pre- and proto-symbolic levels of communication. This void leaves those attempting to enhance communication in people with PIMD little detail on which to base their interventions, and a dearth of sensitive assessments to provide baseline communication information and measure change in this population. Given this challenge, it is crucial that current assessment measures utilized formally and the rationales for their use are investigated. Such

information will enable the generation of assessment approaches which can more reliably map progress and change in communication skills and furthermore be generalized across interventions to be explored in practice and research.

Burton and Sanderson (1998) identified four paradigms that can be used to understand intellectual disability are as follows: ordinary living/normalization, behavioural, functional and developmental. These have relevance for the way language and communication assessment and intervention are addressed. Assessments of early language and communication can be seen as falling broadly into two groups: norm-referenced assessments (Dockrell, 2001) and criterion-referenced assessments (Kaderavek, 2014). Norm-referenced assessments follow continuous *developmental* progression (e.g., CELF, Wiig, Secord, & Semel, 2004; Reynell-III, Edwards, Fletcher, Garman, Hughes, Letts & Sinka, 1997). These assessments do not, typically, address the pre- and proto-symbolic stages (Brady et al., 2012). Criterion-referenced assessments, which determine whether or not the learner can do specific

activities, can therefore be seen as more *functional*. Examples include the Preverbal Communication Schedule (PVCS, Kiernan & Reid, 1987) and the Triple C (Bloomberg, West, Johnson, & Iacono, 2009). Hence, selection of specific assessments can be informed by the underpinning model of communication employed by practitioners.

There is limited research on the developmental trajectory of communication skills in adults with PIMD, though Rondal and Edwards (1997) suggest that some continued progress in “language pragmatics” continues at least into early adulthood. In this paper, therefore, we will adopt a lifespan approach, in which both adults and children are regarded as having the potential for communicative development. This point, in conjunction with the risk of social exclusion, makes an argument for communication intervention with children and adults with PIMD, even if the aim is to increase opportunities for social interaction and enhance performance rather than to increase competence per se. This is reinforced by Bunning’s (2009, p. 48) definition: “Communication is about two or more people working together and coordinating their actions in an ongoing response to each other and the context.” This emphasizes the importance of the active role of the communication partner. However, they may struggle to interpret communicative intent or to respond sensitively to the communicative behaviours of people with PIMD which are often individual and idiosyncratic (De Bortoli, Arthur-Kelly, Foreman, Balandin, & Mathisen, 2011; De Bortoli, Balandin, Foreman, Mathisen, & Arthur-Kelly, 2012; Forster & Iacono, 2008; Healy & Noonan Walsh, 2007; Hostyn, Daelman, Janssen, & Maes, 2010). As a result, people with PIMD can be left socially, societally and educationally excluded. Such communication difficulties can leave people with PIMD unable to influence their surroundings or instigate interactions with others and may ultimately render them devoid of agency. The assessment of communication skills provides a crucial baseline for “two or more people working together” (Bunning 2009, p. 48) by informing them about the learner’s level of communication thus providing the starting point for the coordination of actions and ongoing responses.

Assessment of language and communication is a core professional skill of Speech and Language Therapists (SLTs). A position paper from the Royal College of Speech and Language Therapists (RCSLT) in the UK (Baker, Oldnall, Birkett, McCluskey, & Morris, 2010, p. 10) has identified SLTs as the lead experts on communication for people with intellectual disabilities. Further guidelines by the RCSLT (2006, p. 200) described the purpose of the assessment process as “to identify and collect the requisite range of relevant information through appropriate formal and informal methods including discussion with client/carer and consultation with colleagues.” Amongst other outcomes from assessment, they included identification of the client’s communication profile of strengths and difficulties, any challenges presented by communication in everyday functioning, the capacity for change, opportunities for intervention, information for clinical prioritization, management and planning and forward referral to other agencies (RCSLT, 2006). Moreover, the importance of robust communication assessment in informing and charting evidence-based intervention is well substantiated (Brady et al., 2012; Dockrell & Marshall, 2013). Appropriate assessment selection and use are increasingly seen as part of establishing evidence-based practice.

This has been operationalized through the integration of patient values and clinical expertise with the best available research evidence (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). Currently, there is limited empirical evidence that demonstrates the integration of these three strands in the process of communication assessment selection for people with PIMD. Exploration of the decision making around assessment selection and use by SLTs, the key formal communication assessment practitioners, would help to address this evidence gap.

People with PIMD are a low prevalence and highly heterogeneous group with high demands on specialist services (Timmeren et al., 2017). Guess et al. (1988) found that participants spent less than half their time awake and alert, that is, in behavioural states conducive to learning. This could pose difficulties for robust assessment. Also, challenging for those wishing to conduct assessments are the co-morbid conditions and impairments that this client group are likely to experience which include visual impairments (often cortical, 85%, Van Splunder, Stilma, Bernsen, Arentz, & Evenhuis, 2003), hearing impairments (25%–35%, Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001), epilepsy (50%, Lhatoo & Sander, 2001), neuro-motor impairments (Arvio & Sillanpää, 2003) and gastro-oesophageal disorders (Van der Heide, Van der Putten, Van den Berg, Taxis, & Vlaskamp, 2009). These conditions can also have a negative impact on wellbeing and participation (Zijlstra & Vlaskamp, 2005).

The complexity and heterogeneity of sensory, perceptual, motor and cognitive impairments experienced by people with PIMD suggest that they are unlikely to conform to the standardization sample of published assessments aimed at the wider population of individuals with communication impairments. People with PIMD, who may experience very protracted periods within early developmental stages, cannot be assumed to follow typical trajectories (Brady et al., 2012). Brady et al. (2012) discuss a range of syndromes with non-typical progression, suggesting that researchers and practitioners should, at least, be wary of making developmentally based assumptions. In order to support evidence-based practice, the authors of the Triple C (Bloomberg et al., 2009; Iacono et al., 2009), PVCS (Kiernan & Reid, 1987) and the Communication Complexity Scale (Brady et al., 2012, 2018, still in development) have engaged in some evaluation of the psychometric properties of both assessments.

Despite presenting with complex communication profiles, there appears to be consistency across categorizations of communication in people with PIMD. Using assessment data (Triple C, Bloomberg et al., 2009), from 72 adults aged 20–70 with severe and profound disabilities, Iacono et al. (2009) have demonstrated progression through five stages: unintentional passive, unintentional active, intentional formal, symbolic (basic) and symbolic established. Rowland’s (2013) communication matrix reports on seven levels, from pre-intentional behaviour through to intentional language. The first six of these correspond to the range described in the Triple C comprising pre-intentional behaviour, intentional behaviour, unconventional communication (pre-symbolic), conventional communication (pre-symbolic), concrete symbols and abstract symbols.

Few published communication assessments are available that have been specifically devised for people with PIMD (Iacono et al.,

2009). The reason for this lack of specific assessment availability is unclear, although we hypothesize that it may be as a result of the low incidence of this population (Mansell, 2010). Those with PIMD are a “Cinderella” (i.e., low status) group within a “Cinderella” group (the population of people with an intellectual disability), receiving less attention in both practice and research, compared with others both with and without intellectual disabilities (*cf.* Harflett, Turner, & Bown, 2015). It is also important to note that the complementary use of multiple assessments, for example, the use of eclectic approaches, including formal and informal language assessments and family input, has been advocated in the process of communication assessment of people with PIMD (Brady & Halle, 1997; Brady et al., 2012; Ogletree, Turowski, & Fischer, 1996).

Given the limits of assessment material and the complex needs of this client group, it is unsurprising that there is a lack of clarity within the extant literature regarding communication assessment selection and use. The aim of this paper was to explore how communication assessment was conducted in the UK with people with PIMD across the lifespan by SLTs. A survey was employed in an attempt to establish a picture of current practice of SLTs who worked with children and adults with PIMD and who utilized core assessment as part of their role. Of particular interest was the nature of communication assessments used, and the rationales provided for their selection and use.

1.1 | Research questions

1. What communication assessment approaches were most commonly used by SLTs working with children and adults with PIMD?
2. What rationales were given by SLTs working with children and adults with PIMD for the selection of these assessment approaches?

2 | METHOD

2.1 | Design

For this exploratory investigation, a questionnaire-based survey was used to collect data from SLTs currently in practice. Descriptive information was gathered about the type of assessments chosen and the priorities given for that choice in working with children and adults with PIMD. Questions were asked relating to the source of the assessment material, which client group the clinician used it with and the rationales for its use. Ethical approval was given for this project by South West England Research Ethics Committee.

2.2 | Development and pilot of questionnaire

Discussion at the Special Interest Research Group for Profound and Multiple Learning Disabilities (PMLD) within the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) informed the design of the initial survey. This

was further refined on consultation with a group of three SLTs experienced in working with PIMD and literature on survey design (De Vaus, 2013; Oppenheim, 2000). Responses were requested for the following: (a) name each assessment used with children and/or adults with PIMD and (b) provide the source of the assessment or descriptive information regarding how and why the assessment was created. Participants were asked in open-ended questions to provide their rationales for choosing and using any assessment they named. The same information was requested for assessments in two different categories: (a) published assessments and (b) unpublished assessments. The latter included assessment material devised within the service where the respondent currently worked (in-house assessments), those devised outside the service but unpublished and personally devised assessments. Space was provided at the end of the questionnaire for further relevant descriptive information. Background information about the SLTs was also gathered, comprising the level of experience they considered themselves to have in the area of communication assessment and intervention with people with PIMD, the type of setting they worked in and other stakeholders they collaborated with. The finished survey was piloted with three non-participant SLTs and amended in line with their suggestions to clarify some of the directives and instructions on the questionnaire. No change was made to the content or to the information requested. A copy of the survey can be obtained from the first author upon request. PMLD rather than PIMD was the terminology used within the survey as this was believed to be the terminology most commonly used with the UK context, PIMD has been used in this publication to accord with the journal style.

2.3 | Recruitment and sampling

The regular RCSLT Bulletin, their CPD e-newsletter and RCSLT Special Interest Groups were targeted for dissemination of recruitment information via letter and an invitation for interested SLT participants to contact the principal investigator (PI) directly for further details. No reliable data was available to show the number of SLTs currently working in the UK in this specialist area. Multiple, non-probability sampling techniques were used to maximize response rate for recruitment. The first, purposive self-selected sample of participants were those who self-identified as working with a client group of children or adults with PIMD. This formed the inclusion criterion for the study. To increase recruitment, snowball sampling was also employed, where those who had participated were asked to identify and forward the questionnaire to colleagues and other eligible SLTs they knew of who also worked in the area of PIMD.

2.4 | Participants

Final recruitment resulted in usable surveys from 55 SLTs who worked with children (30) and/or adults (35) with PIMD (10 participants worked with both children and adults). Within this group, participants represented all but two Higher Education Institutions (HEI) that provided accreditation for qualifying SLTs in the UK. No

uncompleted surveys were returned, 52 were fully completed with 3 having some minimal missing data.

2.4.1 | Participant background and experience

Background information about the participant SLTs is presented in Table 1. Most participants had been working as SLTs for 6 years or more, with around a quarter having worked between 3 and 5 years in practice. Few had been in practice for <3 years. With regard to their working week, around two-thirds of participants worked full time with the remainder working part-time (between 1 and 4.5 days per week). Around two-thirds worked with people with PIMD between 0.5 and 4 days per week with most working 0.5 to 2 days per week. One-third of participants reported working with people with PIMD for half a day or less per week. Most participants rated themselves as experienced (96.1%) and skilled (78.9%) in working with people with PIMD in the area of communication.

2.4.2 | Team involvement and the workplace

Participants worked in a variety of environments, some in more than one setting. Most worked in intellectual disability community teams, while some worked in Primary Care Trusts and educational settings. Joint multidisciplinary work was evident across a number of settings. The most frequent partnerships were with physiotherapy, occupational therapy and with the family carers. More than 50% of SLTs reported that they worked closely with teachers, psychologists, community nurses, SLT assistants, day and residential staff and dietitians. Less common was joint work with social workers, care managers, school nurses, nursery staff and psychiatrists. A number of other collaborators were mentioned, each by one respondent.

2.5 | Procedure

Following ethical approval, contact was made with the RCSLT for the distribution of advertising material. This contact took the form of a letter sent via the RCSLT as explained above. Interested participants were encouraged to contact the PI by email or telephone to request further information or a participant pack. Participant packs, comprising the information leaflet, consent form and survey, were sent to all those who agreed to take part by post in paper form, or electronically in digital form, according to participant preference. These packs included a letter of introduction to the study, giving the background and outlining the study's objectives, an information leaflet providing a clear explanation of the expectations from the participant and responsibilities of the project team, a consent form and the survey. All participants were reassured that they could withdraw from the study at any time. A 3-week timescale was given for completion and return of the survey. Follow-up reminders were sent by email after 1 week. On arrival, surveys were separated from personal identifying information and secured in separate locked filing cabinets or password protected folders. All surveys were anonymized and coded. Data

were entered into SPSS on a password protected computer for future reference.

2.6 | Data analysis

Quantitative data were analysed using descriptive statistics. The number of participants using each assessment was determined for each assessment type. The qualitative data from the open-ended questions relating to rationales for using each assessment were then grouped together and conceptually content-analysed using the method outlined by Carley (1990). This involved grouping the rationales into basic themes for each published assessment based on the similarity of response. The number of participants reporting each rationale was recorded for each assessment. Each author took the rationale data for an equivalent number of assessments to code into basic themes. This allowed identification of the specific rationales for each assessment. To enhance the trustworthiness of this analysis, initial coding was repeated for each assessment, with second coding being conducted independently by one of the other authors. Any coding discrepancies were resolved via discussion. The few comments that were difficult to understand and problematic to code, typically due to being unfinished or unclearly articulated, were excluded from the analysis. Subsequently, the first author recoded the initial list of basic themes into organizing themes and then identified which assessments these organizing themes corresponded to (see Table 2). This provided a synthesis of the various rationales across the different assessments. This analysis was also independently checked by the third author, to enhance the credibility and trustworthiness of the findings, with discrepancies once again resolved via discussion. A similar process was undertaken for the content analysis of the unpublished assessments but, due to their individual, idiosyncratic and unpublished nature, only the synthesized rationales are presented in the findings below with frequency and percentages provided relating to the number of participants reporting the theme, rather than the number of assessments that corresponded to particular themes.

3 | FINDINGS

3.1 | Communication assessments used

Over 90% of therapists (50) reported using unpublished assessments with both adults (32; 91%) and children (27; 90%) (nine respondents used unpublished assessments with both children and adults). Slightly fewer (46; 83.6%) reported using published assessments, again with both adults (29; 82.9%) and children (25; 83.3%).

Most of the 55 respondents (42; 76.4%) reported using both published and unpublished assessments of people with PIMD. Typically, multiple methods were used to assess communication with unpublished and published assessments merging into an assessment profile, although this was rarely formally described as such in the surveys. Only five (9.1%) respondents used published assessments only and eight (14.5%) used unpublished assessments alone.

TABLE 1 Showing background information for participants

Background information (N of respondents)	N	%
Client age groups worked with (N = 55)		
Only children	20	36.3
Only adults	25	45.5
Both children & adults	10	18.2
Total working with children	30	54.5
Total working with adults	35	63.6
Experience working as an SLT (N = 52)		
>10 years	23	41.8
6–9 years	8	14.5
3–5 years	14	25.5
2 years or less	7	12.8
Time spent working each week (N = 53; 1 session = ½ a day)		
5 days/10 sessions per week	35	66.0
4–5 days/8–9 sessions per week	6	11.4
1–3.5 days/3–7 sessions per week	12	22.7
Time spent working with people with PIMD each week (N = 40; 1 session = ½ a day)		
2.5–4 days/5–8 sessions per week	2	5.0
0.5–2 days/1–4 sessions per week	24	60.0
<0.5 days/<1 session per week	14	35
Self-rating of experience of working on communication with people with PIMD (N = 52)		
Highly experienced	23	53.8
Experienced	22	42.3
Some experience	5	9.6
Limited experience	2	3.8
Self-rating of expertise and skill working on communication with people with PIMD (N = 52)		
Highly skilled	16	30.8
Skilled	25	48.1
Some skill	6	11.5
Limited skill	5	9.6
Workplace (N = 54)		
Intellectual disability community team	28	51.9
Primary care trusts	26	48.1
Education	14	26.0
Mental health/behavioural team	5	9.1
Collaborative working		
Physiotherapist	43	79.6
Occupational therapist	41	75.9
Family carer	41	75.9
Teachers	35	63.5
Psychologists	36	65.5
Community nurses	32	58.2
SLT assistants	34	61.8
Day & residential support staff	30	54.5
Dieticians	28	50.9
Social worker/care manager	7	12.9
Specialist, nursery and school nurses	5	9.25

(Continues)

TABLE 1 (Continued)

Background information (N of respondents)	N	%
Psychiatrists	3	5.5
All mentioned by a single respondent: Play specialist, school tutor, special educational needs coordinator (SENCO), behaviour specialist, music therapist, sensory support coordinator, "Seeability" worker (for profound cognitive and sensory impairments), medical officer, paediatrician, respite carer, Portage worker and racial minority link worker	1	1.9

Use of unpublished assessments reportedly involved developing new assessments, but it also involved taking a number of existing assessments, adapting each and merging them into a new assessment, or taking an individual published assessment and adapting it. Hence, an eclectic approach to assessment was evident in the work of the SLTs surveyed. The purpose in all cases was to develop, in the opinion of the participant, a more functionally useful assessment. Unpublished assessments were used more often with adults (26; 52%) than children (20; 40%); only three used them with both adults and children (3; 6%). Hence, these tended to be used with *either* adults or children with few using unpublished assessments with both groups. This contrasts with the published assessments, which were more often used with *both* adults and children.

3.2 | Published communication assessment use

A list of all published assessments reportedly used by the respondent clinicians can be seen in Table 2. Appendix 1 provides an overview of the aims, methods, outputs and specific rationales reported by respondents for using each of the different assessments. Only three assessments were cited by more than 5 SLTs: the Preverbal Communication Assessment (25; 45.5%), the Affective Communication Assessment (21; 38.2%) and the Checklist of Communication Competence (Triple C) (9; 16.4%).

Synthesis of the specific rationales provided for using the published assessments resulted in six core motivators for assessment selection and use (Table 2). First, the potential information that could be gleaned about the person's communicative developmental level informed the selection of 16 (59.3%) out of the 27 assessments. Comments were made about assessments being appropriate to the communicative level of people with PIMD because they enabled identification and distinguishing of early communicative developmental stages (7; 25.9%), levels of receptive and expressive communication (5; 18.5%), pre-intentional, intentional and formal intentional communication (3; 11.1%) and vocabulary and grammar use (2; 7.4%).

Second, assessments were selected because they provided information about how the person with PIMD communicated (7; 25.9%). This included identifying specific, personalized communication behaviours used (2; 7.4%), how they communicated their desires and needs (4; 14.8%), how they made choices, indicated

likes and dislikes (2; 7.4%), and demonstrated their communication strengths (3; 11.1%). They also helped them to better understand the specific ways people communicated across different contexts (1; 3.7%).

Third, use of particular assessments supported effective working with communication partners, including family and paid carers and teachers (10; 37.0%). Some assessments were described as helpful for explaining communication levels of the person with PIMD to communication partners. This enabled a shared understanding of the person's communicative behaviours to be reached (8; 29.6%). Assessments were also used in training communication partners and in setting joint goals with them (5; 18.5%). Using assessments in this way was described as helping to build more positive relationships between the clinician and these stakeholders (2; 7.4%).

Fourth, 12 (44.4%) of the assessments were used because they supported and informed the development of communication interventions (10; 37.0%) and provided a baseline against which developmental and functional change (3; 11.1%) and intervention success (3; 11.1%) could be measured.

Fifth, the utility of assessments was a key influencing factor in clinicians' motivation to use them (18; 66.7%). Some assessments were selected based on their "user-friendliness" and because they were easy to use with unfamiliar clients on initial assessment (8; 29.6%). The comprehensiveness in detail, breadth and thoroughness of the information assessments provided was also mentioned (4; 14.8%). Conversely, the brevity of some assessments was deemed a benefit when assessing people with more limited concentration (2; 7.4%). The utility of assessments within educational settings was deemed an important part of some assessments (2; 7.4%) because they mapped onto developmental stages or locally based curricula. Flexibility in how information could be gathered was another consideration (1; 3.7%). A final practical aspect reported was the observational focus and ability to use some assessments to structure observations (5; 18.5%).

Finally, the fact that assessments were underpinned by research evidence was mentioned by one respondent. For only two assessments (7.4%), the fact that they were recognized and research-based was mentioned, although the nature of this research was not provided as part of their rationale for choosing the assessment.

These six drivers and motivators have been summarized corresponding with each assessment in Table 2. Specific rationales given by respondents for choosing each of the published assessments are detailed in Appendix 1.

3.3 | Unpublished assessment use

Unpublished assessments included those solely devised by practitioners and practitioner groups. Assessments developed from pre-existing materials included pre-existing published communication assessments and unpublished assessments that practitioners had not been involved in developing but had used. Almost all of the SLTs using unpublished assessments provided rationales for their use (49; 98%). Eight main themes were identified during the conceptual content analysis of the rationales and explanations for the development of these unpublished assessments as presented below.

3.3.1 | Development of unpublished assessments

Unpublished assessments had in some cases been devised locally prior to participant employment within the particular setting (7; 14.2%). When the respondent had been instrumental in developing an assessment, the contributing factors reported were prior discussion and development with colleagues (14; 28.6) and having developed assessments over time based on their experience as practitioners (14; 28.6%). For the latter, both trial and error over years of experience (2; 4.1%) along with learning, reading and evidence (6; 12.2%) were reported to underpin the development process.

3.3.2 | Adaptation of existing assessments

Some unpublished assessments were reportedly adapted from other communication, developmental or behavioural assessments or from intervention approaches (17; 34.7%). These involved taking existing published assessments and interventions and either modifying them for use with people with PIMD or developing new assessments based on existing assessments or interventions. This need for adaptation was linked to the lack of existing suitable communication assessments and associated materials (17; 34.7%) reported by a number of respondents.

3.3.3 | Observation in unpublished assessments

Informal unstructured and formal structured observations were the primary forms of communication assessment for people with PIMD reported by respondents (31; 63.3%). These observations involved the use of everyday objects (16; 32.7%) gathered from the local environment and kept as a bag or box of materials by the practitioner to be used as part of each assessment. Structured observations incorporated formal methods using checklists and other qualitative and quantitative methods of recording.

3.3.4 | The need for an individual and flexible approach in assessment

Use of unpublished assessments was linked to a need for an individualized and client-led focus when assessing the communication of people with PIMD (13; 26.5%). This sometimes led to inconsistency in approach and was often reported alongside acknowledging the heterogeneity of this group of people. It resulted in the expressed need for a more flexible approach in order to engage the individual during assessments (10; 20.4%).

3.3.5 | Functions of unpublished assessments: 1. Understanding the individual's communication

A further driver and fundamental function of developing unpublished assessments was to understand the individual communication level and preferences of the person. Therapists aimed to gauge the communication preferences and best ways to engage the person with PIMD (8; 16.3%) and to determine their expressive (13; 26.5%) and receptive comprehension (10; 20.4%), including communicative styles and symbolic understanding (8; 16.3%). Unpublished assessments were also used to reveal how communication varied in different environments (2; 4.1%), to identify the functions of communicative behaviours (7; 14.3%) and to show areas of communicative strength and difficulty (10; 20.4%). Unpublished assessments were reported to provide a more comprehensive picture of a person's communication, enabling aspects of communication to be assessed which might otherwise be overlooked with formal measures (12; 24.5%).

3.3.6 | Functions of unpublished assessments: 2. Working towards a unified approach by involving key people in person's environment

Practitioners used informal discussion or developed surveys and checklists with stakeholders to gather information as part of assessments (11; 22.5%). These were conducted with familiar interaction partners and enabled therapists to determine how consistent the description of communication was amongst different stakeholders, thus informally carrying out triangulation of sources (13; 26.5%). Outcomes were used to identify the optimal personal modes of communication and how to ensure that responses were consistent across communication partners in the person's environment. Involvement of key stakeholders in assessment also enabled negotiation of how to move forward along the developmental trajectory in communicating with the person with PIMD. This was reported as a complex decision-making process.

3.3.7 | Functions of unpublished assessments: 3. To provide a baseline from which to compare and track changes in communication

A final function of the unpublished assessments was to provide a baseline from which to compare and track progress and changes

TABLE 2 Showing the number of respondents using each specific type of published communication assessment with children and adults with PIMD and the rationales given for their use

Assessment	Overall		Both		Child		Adult		Provides information about the person's communicative developmental level	Provides information about how the person with PIMD communicates	Rationales	Informs intervention planning and development & provides a baseline against which change/progress can be measured	Pragmatic utility of assessment is evidence based
	N	%	N	%	N	%	N	%					
PreVerbal Communication Schedule (PVCS; Kiernan & Reid, 1987)	25	45.5	2	3.6	8	14.5	15	27.3	✓	✓	✓	✓	✓
Affective Communication Assessment (ACA; Coupe et al., 1985)	21	38.2	4	7.3	10	18.2	7	12.7	✓	✓	✓	✓	✓
Checklist Of Communication Competencies (Triple C; CCC; Iacono et al., 2005)	9	16.4	3	5.5	3	5.5	3	5.5	✓	✓	✓	✓	✓
Individualized Sensory Environment (ISE; Bunning, 1996, 1998)	4	7.3	2	3.6	0	0.0	2	3.6	✓	✓	✓	✓	✓
Pragmatics Profile of Everyday Communication (Dewart & Summers, 1988, 1996)	3	5.5	0	0.0	2	3.6	1	1.8	✓	✓	✓	✓	✓
St Margaret's Curriculum (No reference available)	3	5.5	0	0.0	3	5.5	0	0.0	✓	✓	✓	✓	✓
Early Communication Assessment (ECA; Coupe-O'Kane & Goldbart, 1998)	3	5.5	1	1.8	1	1.8	1	1.8	✓	✓	✓	✓	✓
Supporting Communication through AAC (Hazell & Larcher, 2006)	3	5.5	2	3.7	1	1.8	0	0.0	✓	✓	✓	✓	✓
Test of Receptive Grammar (TROG; Bishop, 2003)	2	3.6	1	1.8	0	0.0	1	1.8	✓	✓	✓	✓	✓
Receptive-Expressive Emergent Language Test (REEL; Bzoch, League, & Brown, 2003)	2	3.6	0	0.0	2	3.6	0	0.0	✓	✓	✓	✓	✓
See What I Mean (SWIM; Grove, Bunning, Porter, & Olsson, 1999)	2	3.6	0	0.0	0	0.0	2	3.6	✓	✓	✓	✓	✓
Communication Profile (For People with learning disabilities; McConkey & Valentine, 2008)	2	3.6	0	0.0	1	1.8	1	1.8	✓	✓	✓	✓	✓
Clinical Evaluation of Language (CELF; Wiig et al., 2004)	2	3.6	0	0.0	1	1.8	1	1.8	✓	✓	✓	✓	✓

(Continues)

TABLE 2 (Continued)

Assessment	Overall		Both		Child		Adult		Provides information about the person's communicative developmental level	Provides information about how the person with PIMD communicates	Rationales	Informs intervention planning and development & provides a baseline against which change/progress can be measured	Pragmatic utility of assessment	Assessment is evidence based
	N	%	N	%	N	%	N	%						
Derbyshire Language Scheme (DLS; Knowles & Masidlover, 1982)	2	3.6	0	0.0	2	3.6	0	0.0	✓	X	✓	✓	X	X
Renfrew Action Picture Test (RAPT; Renfrew, 2011)	2	3.6	0	0.0	2	3.6	0	0.0	✓	X	X	X	✓	X
Redway School's Communication Assessment (no reference available)	2	3.6	0	0.0	0	0.0	2	3.6	X	X	✓	✓	✓	X
Object related Schemes (Coupe & Levy, 1985)	2	3.6	0	0.0	2	3.6	0	0.0	✓	X	X	✓	✓	X
Assessing and Promoting Effective Communication (APEC; Bolton, 2004; Latham & Miles, 1996, 2001)	1	1.8	0	0.0	1	1.8	0	0.0	X	X	✓	✓	✓	X
Boehm—Test of Basic Concepts (Boehm, 1986)	1	1.8	0	0.0	1	1.8	0	0.0	✓	X	X	✓	✓	X
Communication Matrix (Rowland, 2013)	1	1.8	0	0.0	1	1.8	0	0.0	X	✓	X	✓	✓	X
Do-Watch-Listen-Say (Quill, 2000)	1	1.8	0	0.0	1	1.8	0	0.0	X	X	X	X	✓	X
Living Language (Pre-language record book; Locke, 1985)	1	1.8	0	0.0	1	1.8	0	0.0	X	X	X	X	✓	X
PreSchool Language Scales (PLS; Zimmerman, Steiner, & Pond, 2011)	1	1.8	0	0.0	1	1.8	0	0.0	✓	X	X	X	✓	X
Reynell Developmental Language Scales (RDLs; Edwards, Lettis, & Sinka, 2011)	1	1.8	0	0.0	1	1.8	0	0.0	X	X	X	X	✓	X
Symbolic Play Test (SPT; Lowe & Costello, 1988)	1	1.8	0	0.0	1	1.8	0	0.0	✓	X	X	X	✓	X
Communication Assessment Profile (CASP; van der Gaag, 1988)	1	1.8	0	0.0	0	0.0	1	1.8	✓	X	X	X	X	X

in communication (17; 34.7%). Linked to this, individual reports showed that therapists had also developed assessments to enable staff to identify development and change by breaking down skills into smaller steps. This was reported as supporting staff focus on aspects of communication that they might have missed and which could evidence change (2; 4.1%).

3.3.8 | Organizational reasons for using unpublished assessments

Finally, organizational policy influenced the use of assessments and in some cases prompted development of in-house and adapted assessments of communication (8; 16.3%). Lack of resources and time in services to create more complex in-depth assessments led to the development of shorter screening tests and checklists which were quicker and easier to administer (8; 16.3%). The development of in-house assessment recording forms also enabled a more consistent approach within teams of practitioners and encouraged clear record keeping (2; 4.1%).

4 | DISCUSSION

This survey endeavoured to establish a picture of current practice of SLT assessment of communication in people with PIMD. This enabled us to discern consistency and robustness of assessment processes and associated decision making. Being able to generate assessments that can reliably map progress in communication skills and that could be generalized across the work of SLTs would undoubtedly strengthen their potential to define more effective interventions and to research these with more replicability in the future. If taken up by other practitioner and researcher groups, this consistency would also strengthen the accumulating research evidence base.

4.1 | Communication assessment with people with PIMD

The assessment in practice of communication skills is an understudied aspect of PIMD. Three published communication assessments were reportedly most often used by respondent SLTs: the Preverbal Communication Schedule (PVCS; Kiernan & Reid, 1987), the Affective Communication Assessment (ACA; Coupe, Barton, Collins, Levy, & Murphy, 1985) and the Checklist of Communication Competence (Triple C; Iacono et al., 2005). It is difficult to contrast our findings here with non-UK literature because the terminology and criteria around profound intellectual disability vary considerably (Bellamy et al., 2010), and we could not identify parallel research from other parts of the world. All three, and indeed all the assessments reported, are from Anglophone countries (Two from the UK and one from Australia). While at the preverbal level, a non-English language-based assessment would be equally relevant, it is likely that these are more difficult for practitioners to access and use.

With regard to key assessment functions and the assessments most commonly used by respondents ($N > 5$), both the PVCS and the ACA reportedly provided information about developmental levels of communication, information about how individuals communicated, supported communication partner understanding and collaboration and informed intervention planning and the charting of change. Moreover, they were reportedly pragmatically viable to use and supported by evidence. The Triple C assessment also met the majority of the same functions identified, with the exception of providing details of how an individual communicates. It also lacked mention of being an evidence-based assessment, despite the availability of psychometric information (Bloomberg et al., 2009; Iacono et al., 2009). By using these core communication assessments a shared language could be developed to enable a more robust process of communication assessment for people with PIMD to enhance intervention and research.

As expected, the complexity of impairments experienced by people with PIMD leads SLTs to use specialized assessments, designed for this client group, rather than norm-referenced assessments standardized on a typically developing population. In particular, SLTs identified the importance of the in-depth focus on very early communication, which would not be evident in norm-referenced assessments and which typically do not address developmental levels below 18 months (Brady et al., 2012; Dockrell, 2001). The assessments commonly cited by informants in this study all address issues such as the transition from pre-intentional to intentional communication which would be relevant to intervention planning for this client group. In this context, it was surprising to see two SLTs reporting use of the TROG (Bishop, 2003), which begins at a comprehension age of four years.

Rationales for assessment use centred around pragmatic utility and how practical, easy and effective the assessments were in providing fine-grained early-stage communication information about the particular person. Providing a good vehicle for discussing communication and interaction frameworks with carers and family was also cited as a reason. The rationales further indicated that SLTs used assessments, to gauge how an individual communicated and how best to engage with him/her, over and above ascertaining their developmental level of communication and strengths and weaknesses. Assessments were also reportedly used as a baseline for designing and tracking the success of interventions. A mirroring of the key motivational and beneficial aspects of assessments was observed across the published and unpublished assessments.

The rationales indicated some limited fitness for purpose amongst the published assessments used. Many respondents, however, reported using an eclectic mix of published, unpublished and self-devised assessments. This suggests that no single assessment was considered adequate to fully assess all aspects of communication for clients with PIMD. Indeed, using a patchwork of unpublished assessments gathering information from observation, case notes and proxy stakeholder sources, alongside published assessments appeared to be common amongst participants. The robustness of such an eclectic approach and whether assessment practices were individualized to the setting where the SLT worked, their practice experience and approach (e.g., developmental or functional approach to communication

assessment), or to the assessment needs of the individual with PIMD is not fully clear from the data accrued here. SLT assessment practice revealed in this study accords with the use of multiple approaches and holistic assessment involving various stakeholders in evaluating skills in children with complex needs (Brady & Halle, 1997; Brady et al., 2012; DeVeney, Hoffman, & Cress, 2012; Ogletree et al., 1996).

It is notable that unpublished assessments were more often used with older rather than younger people with PIMD. A number of potential reasons may explain this finding, but would require further investigation. Fewer assessments were specifically designed for adults (5; 18.5%) or both adults and children (5; 18.5%) than for children (17; 62.9%) (See Appendix 1), and because of this, there may be more need for unpublished assessments to be developed for adults with PIMD. There may also be more focus on functional assessment in adults rendering some of the more developmentally focused child assessments to be viewed as less useful for practitioners. Nonetheless, there was evidence of some assessments devised for children being used and adapted for adults in participant accounts.

4.2 | Evidence-based assessment

As with interventions for people with PIMD (Goldbart, Chadwick, & Buell, 2014), the needs of this client group and the integral importance of those providing daily support seemed to underpin the choice of communication assessment. The expertise of the respondents, although self-rated, was seldom mentioned as a rationale. This, however, may be incorporated into the pragmatic utility rationale where participants mentioned the assessments they found easier, quicker and more flexible to use based on their experience. Limited use of empirical evidence to support assessment selection decisions was evident, suggesting the need for more work determining the efficacy of different communication assessments for people with PIMD. Perusal of the extant literature revealed limited reliability and validity information in existence for the published assessments. The Triple C, developed for use with adolescents and adults with PIMD, has some published information about its psychometric properties (Iacono et al., 2009) but for other commonly used assessments, psychometric information was not available. It would be useful for SLTs to pay further attention to the published psychometric properties of assessments they select and their relevance to this client group.

For the published assessments, only one SLT referred to both the PVCS and the ACA as “research-based” with more participants (6) reporting learning, reading and evidence as underpinning unpublished assessment development. The robustness and trustworthiness of the literature in informing practice as perceived by the SLTs needs further consideration. It is unclear whether SLTs were considering non-peer-reviewed professional publications such as SLT in Practice and the RCSLT Bulletin as research evidence. Further exploration of what is considered robust evidence in assessment use by practitioners working with people with PIMD is needed.

Of the assessments used with people with PIMD, the PVCS has been out of print for several years, and the ACA is available only

through Melland School (Manchester, UK), although it has been reproduced in part in a number of published books and training programmes (e.g., at <http://complexneeds.org.uk/>). This may reflect the limited commercial viability for assessments for a low prevalence group. The 2nd edition of the Triple C (Bloomberg et al., 2009) has been published and is commercially available, although not through a mainstream publisher. It appears that once practitioners begin to use an assessment they may continue to use it, even if it becomes unavailable. No SLTs reported using the Communication Complexity Scale (CCS; Brady et al., 2012, 2018), but this is not surprising, as it had only been described in the research literature at the time of the survey. As the psychometric properties of this scale are now being published, and appear robust, this would appear to be a valuable addition to the assessment resources available for this underserved group.

4.3 | Limitations & future directions

This study is UK focused and as such cannot be generalized beyond this context. It is difficult to discern the representativeness of the sample due to lack of information regarding the number and distribution of UK SLTs working on communication with people with PIMD. Future research should aim to broaden this work, as assessment use may vary considerably based on setting, geographical location and availability of assessment material.

A further limitation of the present study is that it solely focuses on SLTs as respondents. For younger people with PIMD, teachers are also likely to use communication assessments. Some assessments e.g., Routes for Learning (Welsh Assembly Government, 2006), Assessing Communication in the Classroom (Latham & Miles, 1996), the Communication Development Profile (Child, 2006) and the SCOPE curriculum (Hazell & Larcher, 2006) were seldom mentioned by respondent SLTs but may be commonly used by teachers. Parallel research work investigating assessment use by teachers is indicated. More recent assessments which are available and show promise in this field include the CCS (Brady et al., 2012, 2018; as indicated earlier) and the Scale for Dialogical Meaning Making (Hostyn et al., 2010) neither of which were reportedly used by the respondents here.

As noted, the respondent SLTs were not always clear in their description of rationales and use. For example, in some instances discerning whether a child or adult version of an assessment was being used was not fully articulated. A final point of note is that some assessments reportedly used with people with PIMD were developmentally inappropriate and unlikely to provide beneficial information for this group (e.g., TROG, REEL, CeLF). This led to questions of how and why these assessments had been cited as used which cannot be addressed by the available data.

Utilizing a survey to gather data regarding the rationales for selection of assessments was useful in gaining a breadth of information, although it sometimes led to responses which did not illuminate the thought processes behind assessment decision making (e.g., describing the assessment as useful without explaining why and in what ways it was useful). Nevertheless, this investigation contributes to the existing evidence base, by providing some information about the

clinical rationales for assessment choice and use in a typically underserved and overlooked group. As the questionnaire was devised specifically for this project, the robustness of this approach is difficult to gauge. The questionnaire format may have also led to greater social desirability bias in responses, where practitioners may have reported their most ideal practice. Further research utilizing observational, focus group or interview methodologies may allow more robust, and deeper understanding of assessment practices and the rationales for specific assessment use with people with PIMD to further contribute to the evidence base and guide practice developments in this area.

5 | CONCLUSIONS

Findings from this study showed that therapists in practice were using formal and more flexibly developed informal, unpublished assessments. These were both utilized for unstructured and structured assessment work which often incorporated informal, formal and/or structured observation where everyday objects were used to gauge engagement, comprehension and symbolic understanding. Discussions with key people in the person's life augmented these assessment processes.

Communication assessment and accessing the inner world of people with PIMD are inherently challenging. The need for time-consuming observational work, involving discussion and collaboration with all key communication partners, while under organizational pressure to progress work with numerous clients can all contribute to the difficulties inherent in conducting sensitive and effective communication assessment with people with PIMD. As a result, communication work with this client group may arguably result in innovative, well-considered and structured efforts to assess communication and chart developmental progress with carers. However, it is also possible that due to the pragmatic challenges of assessing communication with this group, less well-considered, unstructured practice may be common. In part, this could be due to the complexity of their communication needs and the lack of clear, usable, practical psychometrically robust measures available. The survey conducted here lends some indirect evidence to both of these assertions. Unstructured work without adequate recording and charting of receptive and expressive communication was identified in a minority of responses, and these may be unlikely to guide therapists and carers towards better understanding of the specific communication needs of the person being assessed. This further highlights the need for more psychometrically valid communication assessments for this group and further development of existing assessments; some such work is underway already (e.g., Triple C, Iacono et al., 2009 and CCS, Brady et al., 2018).

An argument can be made that the complexity of gathering information from people with PIMD is not a valid reason for lack of rigour in assessment approaches. Certainly, for more reliable measurement of therapeutic outcomes and for research purposes, communication assessments with good psychometric properties that are fit for purpose are required. Due to the limited existing evidence base for practitioners and educationalists to draw upon,

further work is urgently needed to fully explore communication assessment that leads to effective intervention with this often overlooked group of people.

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REFERENCES

- Arvio, M., & Sillanpää, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, 47(2), 108–112. <https://doi.org/10.1046/j.1365-2788.2003.00447.x>
- Baker, V., Oldnall, L., Birkett, E., McCluskey, G., & Morris, J. (2010). Adults with learning disabilities (ALD) Royal College of Speech and Language Therapists Position Paper. RCSLT: London.
- Bellamy, G., Croot, L., Bush, A., Berry, H., & Smith, A. (2010). A study to define: Profound and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities*, 14(3), 221–235. <https://doi.org/10.1177/1744629510386290>
- Bishop, D. V. M. (2003). *Test for reception of grammar-2*. London, UK: Pearson.
- Bloomberg, K., West, D., Johnson, H., & Iacono, T. (2009). *Triple C: Checklist of communication competencies*. Box Hill, Vic.: Scope. Revised Edition.
- Boehm, A. E. (1986). *Boehm test of basic concepts: Preschool version*. San Antonio, TX: Psychological Corporation.
- Bolton, G. (2004). *APEC 2: Assessing and promoting effective communication*. UK: Bolton.
- Bradley, H. (1991). *Assessing communication together: Training package*. Penarth, UK: MNHA Publications.
- Brady, N. C., Fleming, K., Romine, R. S., Holbrook, A., Muller, K., & Kasari, C. (2018). Concurrent validity and reliability for the communication complexity scale. *American Journal of Speech-Language Pathology*, 27(1), 237–246. https://doi.org/10.1044/2017_AJSLP-17-0106
- Brady, N. C., Fleming, K., Thiemann-Bourque, K., Olswang, L., Dowden, P., Saunders, M. D., & Marquis, J. (2012). Development of the communication complexity scale. *American Journal of Speech-Language Pathology*, 21(1), 16–28. [https://doi.org/10.1044/1058-0360\(2011/10-0099\)](https://doi.org/10.1044/1058-0360(2011/10-0099))
- Brady, N. C., & Halle, J. W. (1997). Functional analysis of communicative behaviors. *Focus on Autism and Other Developmental Disabilities*, 12(2), 95–104. <https://doi.org/10.1177/108835769701200205>
- Bunning, K. (1996). *Development of an 'individualised sensory environment' for adults with learning disabilities and an evaluation of its effects on their interactive behaviours* (Doctoral dissertation, City University London).
- Bunning, K. (1998). To engage or not to engage? Affecting the interactions of learning disabled adults. *International Journal of Language & Communication Disorders*, 33(Suppl 1), 386–391. <https://doi.org/10.3109/13682829809179456>
- Bunning, K. (2009). *Making sense of communication. Profound intellectual and multiple disabilities: Nursing complex needs*. Chichester: Wiley-Blackwell, 46–61.

- Burton, M., & Sanderson, H. (1998). Paradigms in intellectual disability: Compare, contrast, combine. *Journal of Applied Research in Intellectual Disabilities*, 11, 44–59. <https://doi.org/10.1111/j.1468-3148.1998.tb00033.x>
- Bzoch, K. R., League, R., & Brown, V. L. (2003). *Receptive-expressive emergent language test: Examiner's manual*. Austin, TX: Pro-ed.
- Carley, K. (1990). Content analysis. In R. E. Asher (Ed.), *The encyclopedia of language and linguistics* (Vol. 2, pp. 725–730). Edinburgh, UK: Pergamon.
- Child, C. (2006). *Communication development profile*. Brackley, UK: Speechmark Publishing Ltd.
- Coupe, J., Barton, L., Collins, L., Levy, D., & Murphy, D. (1985). *The affective communication assessment*. Manchester, UK: M.E.C.
- Coupe, J., & Levy, D. (1985). The object related scheme assessment procedure: A cognitive assessment for developmentally young children who may have additional physical or sensory handicaps. *British Journal of Learning Disabilities*, 13(1), 22–24.
- Coupe-O'Kane, J., & Goldbart, J. (1998). *Communication before speech: Development and assessment*. London, UK: David Fulton.
- De Bortoli, T., Arthur-Kelly, M., Foreman, P., Balandin, S., & Mathisen, B. (2011). Complex contextual influences on the communicative interactions of students with multiple and severe disabilities. *International Journal of Speech-Language Pathology*, 13(5), 422–435. <https://doi.org/10.3109/17549507.2011.550691>
- De Bortoli, T., Balandin, S., Foreman, P., Mathisen, B., & Arthur-Kelly, M. (2012). Mainstream teachers' experiences of communicating with students with multiple and severe disabilities. *Education and Training in Autism and Developmental Disabilities*, 47, 236–252.
- De Vaus, D. A. (2013). *Surveys in social research*. London, UK: Routledge.
- Department for Education (2014). *Training materials for teachers of learners with severe, profound and complex learning difficulties*. Retrieved from <http://complexneeds.org.uk/>
- DeVeney, S. L., Hoffman, L., & Cress, C. J. (2012). Communication-based assessment of developmental age for young children with developmental disabilities. *Journal of Speech, Language, and Hearing Research*, 55(3), 695–709. [https://doi.org/10.1044/1092-4388\(2011/10-0148\)](https://doi.org/10.1044/1092-4388(2011/10-0148))
- Dewart, H., & Summers, S. (1988). *The pragmatics profile of early communication*. Windsor, UK: NFER Nelson.
- Dewart, H., & Summers, S. (1996). *The pragmatics profile of everyday communication skills in adults*. Windsor, UK: NFER Nelson.
- Dockrell, J. E. (2001). Assessing language skills in preschool children. *Child Psychology and Psychiatry Review*, 6(2), 74–85.
- Dockrell, J. E., & Marshall, C. R. (2015). Measurement issues: Assessing language skills in young children. *Child and Adolescent Mental Health*, 20(2), 116–125.
- Edwards, S., Garman, M., Hughes, A., Letts, C., & Sinka, I. (1999). Assessing the comprehension and production of language in young children: An account of the Reynell Developmental Language Scales III. *International Journal of Language & Communication Disorders*, 34(2), 151–171.
- Edwards, S., Letts, C., & Sinka, I. (2011). *The new Reynell developmental language scales*. London, UK: GL Assessments.
- Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45(5), 457–464. <https://doi.org/10.1046/j.1365-2788.2001.00350.x>
- Forster, S., & Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual and Developmental Disability*, 33(2), 137–147. <https://doi.org/10.1080/13668250802094216>
- Goldbart, J., Chadwick, D. D., & Buell, S. (2014). Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. *International Journal of Language & Communication Disorders*, 49(6), 687–701. <https://doi.org/10.1111/1460-6984.12098>
- Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 12(3), 190–203. [https://doi.org/10.1111/\(ISSN\)1468-3148](https://doi.org/10.1111/(ISSN)1468-3148)
- Guess, D., Mulligan-Ault, M., Roberts, S., Struth, J., Siegel-Causey, E., Thompson, B., ... Guy, B. (1988). Implications of biobehavioral states for the education and treatment of students with the most profoundly handicapping conditions. *Journal of the Association for Persons with Severe Handicaps*, 13(3), 163–174. <https://doi.org/10.1177/154079698801300306>
- Harflett, N., Turner, S., & Bown, H. (2015). *The Impact of Personalisation on the Lives of the Most Isolated People with Learning Disabilities: A Review of the Evidence*. Bath, UK: National Development Team for Inclusion.
- Hazell, G., & Larcher, J. (2006). Supporting Communication through AAC. Communication Aids Project UK: SCOPE. Retrieved from <http://www.scope.org.uk/education/aac.php>
- Healy, D., & Noonan Walsh, P. (2007). Communication among nurses and adults with severe and profound intellectual disabilities: Predicted and observed strategies. *Journal of Intellectual Disabilities*, 11(2), 127–141. <https://doi.org/10.1177/1744629507076927>
- Hostyn, I., Daelman, M., Janssen, M. J., & Maes, B. (2010). Describing dialogue between persons with profound intellectual and multiple disabilities and direct support staff using the scale for dialogical meaning making. *Journal of Intellectual Disability Research*, 54(8), 679–690. <https://doi.org/10.1111/j.1365-2788.2010.01292.x>
- Iacono, T., West, D., Bloomberg, K., & Johnson, H. (2009). Reliability and validity of the revised Triple C: Checklist of communicative competencies for adults with severe and multiple disabilities. *Journal of Intellectual Disability Research*, 53(1), 44–53. <https://doi.org/10.1111/j.1365-2788.2008.01121.x>
- Iacono, T., Bloomberg, K., & West, D. (2005). A preliminary investigation into the internal consistency and construct validity of the Triple C: Checklist of communicative competencies. *Journal of Intellectual and Developmental Disabilities*, 30, 127–138.
- Kaderavek, J. N. (2011). *Language disorders in children: Fundamental concepts of assessment and intervention*. Pearson/Prentice.
- Kiernan, C., & Reid, B. (1987). *Preverbal communication schedule (PVCS)*. Windsor, UK: NFER.
- Knowles, W., & Masidlover, M. (1982). *The Derbyshire language scheme*. Derby, UK: Derbyshire County Council.
- Latham, C., & Miles, A. (1996). *Assessing communication*. London: University of West Virginia: David Fulton Pub.
- Latham, C., & Miles, A. (2001). *Communication, curriculum & classroom practice*. London: University of West Virginia: David Fulton Pub.
- Lhatoo, S. D., & Sander, J. W. A. S. (2001). The epidemiology of epilepsy and learning disability. *Epilepsia*, 42(S1), 6–9. <https://doi.org/10.1046/j.1528-1157.2001.00502.x>
- Locke, A. (1985). *Living language programme*. Windsor, UK: NFER Nelson.
- Lowe, M., & Costello, A. J. (1988). *Symbolic play test*. Windsor, UK: NFER.
- Maes, B., Lambrechts, G., Hostyn, I., & Petry, K. (2007). Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature. *Journal of Intellectual and Developmental Disability*, 32(3), 163–178. <https://doi.org/10.1080/13668250701549427>
- Mansell, J. (2010). Raising our sights: Services for adults with profound intellectual and multiple disabilities. *Tizard Learning Disability Review*, 15(3), 5–12.
- McConkey, R., & Valentine, J. (2008). *The communication profile for people with intellectual disabilities: Access to participation through working with communication partners*. Milton Keynes, UK: Speechmark.

- Ogletree, B. T., Turowski, M., & Fischer, M. A. (1996). Assessment targets and protocols for nonsymbolic communicators with profound disabilities. *Focus on Autism and Other Developmental Disabilities*, 11(1), 53–58. <https://doi.org/10.1177/108835769601100107>
- Oppenheim, A. N. (2000). *Questionnaire design, interviewing and attitude measurement*. London, UK: Bloomsbury Publishing.
- Quill, K. A. (2000). *Do-watch-listen-say: Social and communication intervention for children with autism*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007). Understanding distress in people with severe communication difficulties: Developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research*, 51(4), 277–292. <https://doi.org/10.1111/j.1365-2788.2006.00875.x>
- Renfrew, C. E. (2011). *Action picture test*. Milton Keynes, UK: Speechmark.
- Rondal, J., & Edwards, S. (1997). *Language in mental retardation*. London, UK: Whurr.
- Rowland, C. (2013). 'Communication Matrix'. Portland, OR: Design to Learn. Retrieved from www.communicationmatrix.org/
- Royal College of Speech and Language Therapists (RCSLT) (2006). *Communicating Quality 3*. London, UK: RCSLT.
- Sackett, D. L., Straus, S. E., Richardson, W. S., Rosenberg, W., & Haynes, R. B. (2000). *How to practice and teach EBM*. Edinburgh, UK: Churchill Livingstone.
- Timmeren, E. A., Schans, C. P., Putten, A. A. J., Krijnen, W. P., Steenbergen, H. A., Schroyensteyn Lantman de-Valk, H. M. J., & Waninge, A. (2017). Physical health issues in adults with severe or profound intellectual and motor disabilities: A systematic review of cross-sectional studies. *Journal of Intellectual Disability Research*, 61(1), 30–49. <https://doi.org/10.1111/jir.12296>
- van der Gaag, A. (1988). *CASP: The communication assessment profile for adults with a mental handicap*. London, UK: Speech Profiles Limited.
- Van der Heide, D. C., Van der Putten, A. A. J., Van den Berg, P. B., Taxis, K., & Vlaskamp, C. (2009). The documentation of health problems in relation to prescribed medication in people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 53, 161–168. <https://doi.org/10.1111/j.1365-2788.2008.01141.x>
- Van Splunder, J., Stilma, J. S., Bernsen, R., Arentz, T. G., & Evenhuis, H. M. (2003). Refractive errors and visual impairment in 900 adults with intellectual disabilities in the Netherlands. *Acta Ophthalmologica*, 81(2), 123–130. <https://doi.org/10.1034/j.1600-0420.2003.00035.x>
- Welsh Assembly Government (2006). *Routes for Learning: Assessment Materials for Learners with Profound Learning Difficulties and Additional Disabilities*. Cardiff, UK: Welsh Assembly Government, Qualifications and Curriculum Group, DELLS (Dept of Education, Lifelong Learning and Skills).
- Wiig, E. H., Secord, W., & Semel, E. M. (2004). *CELF preschool 2: Clinical evaluation of language fundamentals preschool*. Toronto, ON: Pearson/PsychCorp.
- Zijlstra, H. P., & Vlaskamp, C. (2005). Leisure provision for persons with profound intellectual and multiple disabilities: Quality time or killing time? *Journal of Intellectual Disability Research*, 49(6), 434–448. <https://doi.org/10.1111/j.1365-2788.2005.00689.x>
- Zimmerman, I. L., Steiner, V. G., & Pond, R. E. (2011). *PLS-5: Preschool language scale-5 [measurement instrument]*. San Antonio, TX: Psychological Corporation.

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APPENDIX 1

Showing additional information for each assessment reported by SLTs as used with people with PIMD

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
PreVerbal Communication Schedule (PVCS)					
Kiernan and Reid (1987), Currently out of print. Profile available at [http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/B/downloads/m08p030b/the_pvcs.pdf Accessed 21/04/2016]	All ages	Performance on 27 areas of "pre-communicative," informal communicative and formal communicative behaviours, from very early underpinning skills to communication through signs, symbols and words	Rating of performance in discussion with familiar person, e.g., family member, teacher, care staff, and direct testing of some items	Profile indicating strengths and limitations across the 28 areas assessed. Scores on six communicative functions: Attention Seeking, Needs Satisfaction, Simple Negation, Positive Interaction, Negative Interaction and Shared Attention.	Rationales were varied but coherent. The PVCS was regarded by six people as comprehensive or detailed, and as providing guidance on early communication development (3). It was regarded as available (4) and well known (1). Only one SLT identified the PVCS as research-based. Others noted that it was appropriate to the level of clients, that it was developmentally based (1) and also that it was functional (1). Three SLTs reported that it was "useful," with others commenting on specific utility; in informing intervention (5), in informing and education staff and SLT students (5) and in establishing relationships (1) and joint goal setting (1) with families. It was regarded as easy to use with unfamiliar clients (1) and as providing a useful starting point or baseline (2). The profile within the assessment was regarded as identifying strengths and needs across areas of communication (3) and in plotting progress (2). Three SLTs used the assessment to differentiate between pre-intentional, intentional and formal communication or to identify the client's overall level (1). One used the PVCS to structure observational assessments and one described using it in combination with the Redway assessment to provide a different perspective
Affective Communication Assessment (ACA)					
Coupe et al. (1985), Available from Melland High School, 50 Wembley Road Gorton Manchester M18 7DT, UK	Children (though used more widely)	Pre-intentional communication; physical, facial and vocal responses to an individualized set of stimuli; events, people, actions, sensations	Observation, preferably using video, and coding of these affective (emotional) responses by familiar people	Interpretation of these responses as conveying "like," "dislike," "want," "reject" and other. These interpretations can then be assessed against another set of stimuli to identify clusters of behaviours that can be interpreted as like, dislike etc. Reliability data available in Coupe-O'Kane and Goldbart (1998). Communication before Speech. London: Fulton	The rationales given for using the ACA were varied but often connected. The thorough, comprehensive and detailed nature of the assessment was commented on by SLTs (4) with many (11) describing the assessment as useful in one way or another. More specifically that it was designed for people with PIMD (2) and there was currently little available for people with PIMD (4). The fact that it was research-based, and a recognized assessment was also mentioned (1). The ACA reportedly had utility at the initial assessment during the first meeting and acted as a starting point when working with people with PIMD (2), helping to identify the communicative behaviours of this group (2) and helping to determine the person's strengths and needs (1). Ways in which the ACA contributed to and informed assessments were also noted by some SLTs. Going through the ACA together was said to help improve relationships with family and staff (2), be useful in training (3) and it was said to support intervention choice (2). The developmental nature of the assessment (1) and that it provides a baseline, allowing progress to be tracked, and goal and target setting (5) were also given as reasons for its use. Finally, indirect reasons for its use were provided, these were that it provides an alternative viewpoint and additional information (2) and that the SLT gave it to students to use when teaching (1)

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
Triple C: Checklist of Communicative Competencies (CCC)					
Bloomerberg et al. (2009) and Psychometric properties reported in Iacono et al. (2009)	Adults	Detailed checklist of early communicative responses and behaviours, organized by five levels: Unintentional passive communication, Unintentional active communication, Intentional informal communication, Basic symbolic communication to Established symbolic communication	Checklist to be carried out by familiar people, who have known the client for at least 6 months. Involvement of a "communication specialist" is recommended but not required	Scores indicate level of communication: from "Unintentional passive communication, Unintentional active communication, Intentional informal communication, Basic symbolic communication to Established symbolic communication." Feeds into <i>InterAction: Strategies for Intentional and Unintentional Communicators</i> Bloomerberg, K., West, D. & Johnson, H. Scope Vic/Spectronics Inclusive Learning Technologies	Three out of the 9 SLTs who said they used the CCC (or Triple C) for assessment also identified it as most useful for its breakdown of developmental stages, particularly relating to pre-intentional and intentional communication and early functioning. One clinician found it difficult to use because it focuses on physical and sensory information but others found it quick to use (2). Two therapists mentioned the CCC's flexibility as one of the reasons they used it; being able to collect information through direct observation, liaison with others and by setting up situations that could provide baseline measures for future progress. Other reported reasons were that it was good for explaining communication levels to carers (1) and that the detailed developmental steps provided fed into intervention (1)

Individualized Sensory Environment (ISE) Not commercially available Bunning (1996, 1998)	Adults	Observational assessment identifying distribution of time across five levels or forms of engagement: self-neutral, self-active, person, object, person-object	Designed for adults. Detailed observations of engagement in different contexts (momentary time sampling)	Leads directly into the ISE approach to intervention	Respondents identified its usefulness in establishing likes and dislikes (2) and also as a valuable way of establishing pre-intentional and intentional communication levels (3). One therapist reportedly found that knowledge from the ISE approach about intentional communication fed easily into planning for intervention
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Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
Pragmatics Profile of Everyday Communication Dewart and Summers (1988, 1996). Children's version downloadable from http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/downloads/m08p080c/the_pragmatics_profile.pdf (Accessed 01/03/17)	Two versions: Children & adults	The child's communicative functions, how they respond to others' communication, interaction strategies and the impact of context on communication	Informal but structured interview eliciting information from teachers, parents or other familiar people	Not intended to be standardized. Skills in the four areas are summarized in a profile sheet	The reasons given for use included that it provides insight into how the person with PIMD communicates. Another SLT mentioned that the findings from the pragmatics profile can be used to compare the communication of people with PIMD across settings (1). All those that used it reported that it was useful to use with family members and staff supporters (3) and that it provides a joint understanding of the person with PIMD's communication (1)
St Margaret's Curriculum (Renamed as "The Children's Trust"): Unclear if this is the IMPACTS curriculum currently used by the school. See https://www.thechildrenstrust.org.uk/our-curriculum-	Children	No detail publicly available Communication is listed as one of five Key Skill Areas in the IMPACTS programme	No information available	The assessment is an integral part of the curriculum	The assessment was viewed as detailed (1) and appropriate for the client group (1). Two SLTs identified its utility in informing intervention and one that it was helpful in identifying the child's communication level
Early Communication Assessment (ECA) In Coupe-O'Kane and Goldbart (1998)	Children	Detailed checklist of communication behaviours organized to check for consistency of responses and levels of intentionality in communication from pre-intentional through to fully intentional	Observation and direct elicitation by familiar people using a variety of sensory stimuli	Maps onto intervention approaches described in the source book	All three clinicians commented on how easy the ECA was to use, especially for clients functioning at lower cognitive levels. They liked the fact that it was broken down into small steps and one SLT remarked that there were very few suitable alternatives for assessing at this level

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
SCOPE Supporting Communication through AAC Hazell and Larcher (2006). Communication Aids Project UK: SCOPE)	Children & adults	A full package for assessing needs with a view to providing AAC. Module 9 comprises frameworks for assessing communication of children and adults with PIMD using a range of behaviour checklists linked to national curriculum P Levels	Close observation of the individual's behaviours in a variety of contexts over a period of time	Detailed developmental checklists used to establish baseline of behaviours. These are described and matched to P-Levels. Summary charts are provided to track progress across "milestones"	A respondent used this to assess the kind of visual support that a client requires, namely assessing the appropriate symbol size to use with clients (1). Another used it to establish what type of AAC a child might be able to access and at what level (1)
Test of Receptive Grammar (TROG) Bishop (2003)	Children	Measures the understanding of 20 grammatical constructs 4 times each using pictures Multiple choice picture material is shown, requested to point to the correct picture in relation to a spoken statement	Specific ability to understand grammatical concepts without the help of context	Standardized test with age norms	SLTs reported using the TROG as an aid to comprehension assessment (2), despite the TROG developmentally only beginning at four years of age. This indicates it was used with people with severe to moderate cognitive impairment rather than PIMD
Receptive-Expressive Emergent Language Test (REEL) Bzoch et al. (2003)	Children	Developmental test designed to identify infants and toddlers who have language difficulties. Provides breakdown of small stages in early language development	Results obtained from caregiver interview	Norm referenced to provide age equivalents	Although both SLTs who reported using this assessment did so to determine individual children's level, one regarded the steps in the assessment as too large. The other found that the assessment identified the next step to work on. S/he also used it in joint observational assessment with parents
See What I Mean (SWIM) Grove et al. (1999) (out of print)	Children & adults	Guidelines for ascribing meaning to communication in context of decision making. Sets of procedures provided for gathering info, for creating formal discussion and for checking interpretations	Interviews and discussion with caregivers, key people, Consensus discussions, Observations	Protocols/forms provided for gathering relevant descriptive information from a variety of sources to reach consensus on how person communicates: level of intent, with or without physical prompt, ability to persist in communication	SLTs described using SWIM as an assessment tool because it is useful for gathering initial information (2). Therapists also used it as a tool for empowerment, advocacy and awareness raising, through its focus on identifying communication skills in clients with PIMD, this led to opportunities for choice and decision making. This second aspect was noted as the most important aspect of this tool by the therapists who also commented that SWIM was a good tool to demonstrate these skills and abilities to carers and family members

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
Communication Profile (for people with learning disabilities) McConkey and Valentine (2008) (No longer available)	Adults	Part 1 provides a joint framework for dialogue around communication issues. Part 2 is a one-page user-friendly summary sheet which encapsulates this discussion, giving an overview of understanding and expressive communication in basic practical terms	Information gathered through discussion with a range of key communication partners	Descriptive profile of expressive and receptive communication skills leading to clear aims for intervention, planning, charting change, and training	Clinicians stated that they used the Communication Profile because they found it "user-friendly", simple and it provided useful summary information for education professionals and family. One SLT commented that the link with curriculum P-Levels (English Statutory Performance Scales for pupils with PIMD designed to indicate developmental level) was also an advantage
Clinical Evaluation of Language (CELF PreSchool) Wiig et al. (2004)	Children	Measures broad range of expressive and receptive language skills in young children; Subtests include: sentence structure, word structure, vocabulary, following directions, recalling sentences, phonological awareness	A range of picture and auditory prompts are provided to test both receptive and expressive language skills	Standardized norms provided	SLTs reported using the CELF but it was apparent from their rationales that they used it with less cognitively impaired people with intellectual disability
Derbyshire Language Scheme (DLS) Knowles and Masidlover (1982)	Children	Primarily an intervention programme (Levels 1–10) that starts with assessment of early expressive and receptive language levels	Combination of picture and toy stimulus material that are pointed to, responded to verbally or moved/manipulated by person being tested	Expressive and receptive levels of language measured by use and understanding 1–4 information carrying words. Not standardized	The DLS was regarded as useful in assessing comprehension (2) and informing therapy (2). One SLT also used it to inform parents and teachers of the appropriate level of language to use with a child
Renfrew Action Picture Test (RAPT) Renfrew (2011)	Children	Provides samples of spoken language that can be evaluated in terms of grammar and language content: use of nouns, verbs, prepositions, tense, irregular forms of plurals and tense, simple and complex sentence construction, passive voice	A series of pictures are shown to the client with set questions designed to elicit the target response	Designed for 3- to 8-year-olds; standardized norms provided	Therapists reported using the RAPT because they found it a good assessment to gauge expressive language level, it was also used to assess use of grammar. Because it was a short test it was considered useful with people more limited concentration

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
Redway School's Communication Assessment (No Reference available)	Children	Unclear whether this is the same as APEC below. No further information available	No further information available	No further information available	One respondent reported using Redway School's assessment because there was a dearth of suitable approaches for this client group and because it was collaborative, holistic, universal, and had an education focus. It was regarded as useful in presenting a child's level to teachers (1) and developing interventions collaboratively (1)
Object Related Schemes Coupe and Levy (1985)	Children (but widely used with adults)	Piaget-based assessment of cognitive development during the sensori-motor period	Observation of behaviours in response to a range of objects. Familiar adult presents a series of elicitation activities	Level of cognitive development in months, as determined by "schema age;" the age that corresponds to the most sophisticated scheme shown	Both therapists that identified Object Related Schemes worked with children. One found that it provided good information on "learner schemes" or when observing children with objects and the other stated that it gave quick information on the child's cognitive level and could be easily translated into intervention using objects
Below are assessments mentioned by 1 SLT					
Assessing and Promoting Effective Communication (APEC) Bolton, G. (2004). APEC 2 (Assessing and Promoting Effective Communication; APEC references unavailable) (as developed at The Redway School by Latham & Miles, 1996, 2001; David Fulton Publishers)	Children	APEC is a course introducing an assessment framework and teaching approaches. It covers developmental stages, breakdowns in language and using context to develop language	No further information available	No further information available	This assessment was favoured because of its links with the national curriculum which leads easily into setting goals for use within the child's communication environment. It was reported as easy use and as such, good for use with teachers, to train other staff and with families for joint observation
Boehm—Test of Basic Concepts Boehm (1986)	Children	Used to identify clients who might be at risk of learning difficulty. Assesses 26 basic linguistic concepts at 2 age levels: 3 and 4–5. e.g. same/different, more/less, before/after missing	Verbal instruction is presented to the child with picture material e.g., how are these things the same?	Provides information on understanding of linguistic concepts Standardized	This was used by the SLT to assess children's understanding of concepts. It was found easy to use and helped to identify areas for intervention

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
Communication Matrix Rowland (2013)	Children & adults	Free assessment tool to provide communication status, progress, and unique needs of early stage communication. Online checklist of communication behaviours	Observation and completion by family member or carer	Descriptive profile of communication behaviours	This was mentioned for its easy use in assessing communicative functions and means with this information feeding into new target setting, while at the same time providing a baseline for evaluation
Communication Assessment Profile (CASP) van der Gaag (1988)	Adults	Assessment of communicative abilities of adults with severe to mild intellectual disabilities. Part 1 Questionnaire on communication environment; Part 2: photographs and material to assess understanding and use of language	Questionnaire completed by carer/ keyworker Part 2 by SLT to gather information about language Part 3 by carer/client and SLT as a discussion document	Final outcome is a profile of language strengths and weaknesses percentile rank, communication environment rating scale and outline of priorities for change Standardized assessment	This was used with adults with PIMD to determine comprehension of vocabulary and sentence length
Do-Watch-Listen-Say Quill (2000)	Children	Provides checklist for the assessment of social and communication skills./early developmental milestones	Observation	Information about early developmental levels of social and communication skills	This was reportedly useful for structuring observations.
Living Language (Pre-language record book) Locke (1985) (Out of print)	Children	Provides an assessment with pictures "First words" and a pre-language teaching manual "Before Words" along with record booklets	No further information available	No further information available	Living Language (Pre-language record book): This was seen as a quick way to gain an overall idea of the skills and progress of clients
PreSchool Language Scales (PLS) Zimmerman et al. (2011)	Children	Interactive assessment of developmental language skills from birth to 7;11	Pointing or verbal response by client to pictures or objects	Scores for total language, auditory comprehension, expressive communication (standard scores) growth scores, percentile range and age equivalents	This was reportedly less linguistically challenging for children compared to other assessments, while still allowing a detailed assessment of some aspects of language

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
Reynell Developmental Language Scales (RDLS) Edwards et al. (2011)	Children	Identifies speech and language delay and impairment in young children. Tests for expressive and receptive language abilities. Has multilingual toolkit	Uses toys/objects and pictures. Clients point or respond verbally to prompts	Standardized scores for receptive and expressive language (Aged 2-7;6)	Only parts of the Reynell were used by the SLT who mentioned it. One of the main advantages was its accessibility in terms of eye pointing (at the pictures), with the caveat that the assessment does need to be adjusted to the particular needs of each child
Symbolic Play Test (SPT) Lowe and Costello (1988)	Children	Test to identify early skills required for language development; uses play with miniature objects in 4 different situations	Observation of play with small objects presented systematically to the client on 4 occasions	Standardized score for levels of concept formation or symbolization observed through play	This was chosen for its low linguistic demands on children, and the specific information that could be gained about early play and conceptual development
Use of Language questionnaire Non-verbal communication schedule (No reference available)	Not known	No further information available	No further information available	No further information available	None given
Assessing Communication Together (ACT) Bradley (1991)	Adults	Training package that included "Communication" as one section out of 6 all related to meeting the needs of adults with PIMD. Within this, was "assessing and developing communication"	No further information available	No further information available	None given
Non communication focus					
P-scales UK Department for Education, (2014), Performance - P Scale attainment targets for pupils with special educational needs at gov.uk	Children	Breakdown of curriculum targets into very small incremental steps	For use by teachers: descriptors of targets available for all areas of the curriculum for assessment and planning purposes	Information related to curriculum targets at P-scale level	P-Scales provided a shared language for joint work and joint target setting between education colleagues and the SLT who mentioned using them. There is an acknowledgement that P-Scales are not formally considered an assessment, but the value of including teachers and Learning Support Assistants in making "best fit" judgments based on their knowledge of the child proved useful

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APPENDIX 1 (Continued)

Assessment & Reference	Target group ^a	Information gathered	How information is gathered	How information is analysed & data output	Specific rationales given for choosing published assessments
DisDAT Disability Distress Assessment Tool Regnard et al. (2007) (Northumberland Tyne and Wear HNS Trust & St. Oswalds Hospice).	Adults (but may be used with children)	Provides carers with details about how adults with PIMD might show that they are experiencing pain	Structured observation of individuals	Appearance and behaviour when content is contrasted with appearance and behaviour when person is distressed. The Clinical decision distress checklist is used to hypothesise possible causes of distress so they can be managed. A 5-level statement on communication level is included	None given

^aWe have indicated the groups for which the assessments were initially developed. This does not necessarily mean they are inappropriate for other age ranges, where this is the case we have indicated this. Clinician and professional judgements will have bearing on this decision.