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## **Special Issue**

# The proportion of minimally verbal children with autism spectrum disorder in a community-based early intervention programme

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### Abstract

Background Estimates of the proportion of children with autism spectrum disorder (ASD) who are minimally verbal vary from 25%to 35%. However, there is a lack of consensus in defining minimally verbal and few detailed reports of communication outcomes for these children following intervention. The aim of this study was to explore how minimally verbal children have been defined and to document the proportion of minimally verbal children in a group of children with ASD receiving a community based early intervention programme.

Method A longitudinal cohort design was used to examine the proportion of children who met criteria for minimally verbal in 246 children with ASD when they entered and exited an early intervention programme.

Results Overall, 26.3% of the children in this study exited the programme using 'fewer than five spontaneous and functional words' and 36.4% exited not using 'two word phrases' as indicated by direct assessment. However, our findings were mixed

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depending on measures and definitions used, with parent report indicating that as many as 29.4% of children were not 'naming at least three objects' consistently, and 43.3% not using 'phrases with a noun and verb' consistently at exit. More than half of the children who entered the programme with minimal speech exited the programme with a similar language profile. A small percentage of children (1.2%–4.7%) regressed in their language level over time. Conclusions Despite advances in early intervention, and access to services at a younger age, around a quarter of individuals with ASD in this study exited early intervention with significant communication needs. Our findings are considered in relation to the literature and clinical implications, and future research directions are discussed.

**Keywords** autism spectrum disorder, communication, early intervention, minimally verbal, non-verbal, preschool

### Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by impairments in social communication development,

and restrictive and repetitive behaviour patterns (American Psychiatric Association 2013). Signs of ASD are usually observable under 3 years of age (American Psychiatric Association 2013), and early diagnosis provides the opportunity for children to access intervention at an early age (Dawson 2008; Rogers & Vismara 2008). While there is evidence to suggest that early intervention positively impacts on communication and cognitive development in individuals with ASD, individual differences in response to intervention are apparent (Trembath & Vivanti 2014). An important area of heterogeneity is in the area of spoken language (Kjelgaard & Tager-Flusberg 2001; Paul et al. 2013). Early language skills are an important predictor of later outcomes, and children presenting with complex communication needs are more likely to have associated intellectual disabilities that may impact on their social learning experiences, and communication and cognitive abilities later in life (Luyster et al. 2008; Fernell et al. 2013).

In research, communication outcomes for children with ASD are commonly reported using total scores derived from standardised assessments (Matson et al. 2010), including from communication (e.g. Preschool Language Scales) and social communication measures (e.g. Communication and Symbolic Behaviour Scales). These overall scores may fail to capture individual variability in spoken language outcomes (Charman et al. 2003) and may not be appropriate for assessing minimally verbal children with ASD (Charman et al. 2003; Abbeduto et al. 2011; Kasari et al. 2013). Tager-Flusberg et al. (2009) proposed a set of 'spoken language benchmarks' relating to key developmental stages (i.e. first words, word combinations and sentences) aimed at better characterising the language abilities of children with ASD. These benchmarks highlight the importance of documenting and understanding the variability in language outcomes for children with ASD, particularly those who exit early intervention programmes with minimal spoken language.

Norrelgen et al. (2014) identified two key barriers to documenting and understanding language outcomes for children with ASD who exit intervention programmes with minimal spoken language. First, they noted that as a group, children who use little or no spoken language have been inconsistently defined using a variety of terms including 'minimally verbal' (e.g. Goods et al. 2013; Kasari et al. 2013; Paul et al.

2013; Kasari et al. 2014; Norrelgen et al. 2014; Woynaroski et al. 2015); 'non-verbal' (Jonsdottir et al. 2007; Norrelgen et al. 2014); and 'low verbal' (Yoder & Stone 2006). The common element across definitions is the specification of the maximum number of spontaneous functional words a child uses (ranging from 5-20 words) as observed during a natural language sample and/or parent report (refer to the Appendix for expanded definitions). Kasari et al. (2013) operationalised 'minimally verbal' as 'fewer than 20 functional words' (p. 2) for research purposes; however, noted that in clinical contexts the 'exact number of words used does not matter that much' (, p. 2) and depends on a range of individual factors. In this article, we used the Kasari et al. (2013) definition to identify and review relevant studies relating to children who used 'a very small repertoire of spoken words or fixed phrases that are used communicatively' (Kasari et al. 2013, p. 2).

The second barrier Norrelgen et al. (2014) identified is the lack of empirical data reporting on communication outcomes for this group of children. Indeed, there are few, and inconsistent, reports of the prevalence of children with ASD who are minimally verbal in the population or at exit from early intervention. Historically, it was suggested that 50% of individuals with ASD did not develop functional language (Rutter 1978). However, with the advent of earlier identification and intervention, more recent estimates put the figure closer to 25%-30% (Lord et al. 2004; Anderson et al. 2007; Norrelgen et al. 2014), yet some studies are still reporting figures of up to 50% (Kjelgaard & Tager-Flusberg 2001; Magiati et al. 2011). Differences in definition, measurement, sample characterisation and age make comparisons across studies difficult (Jonsdottir et al. 2007; Norrelgen et al. 2014).

Anderson *et al.* (2007) conducted a longitudinal study of expressive language skills in 206 children with ASD, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and other Developmental Disabilities (DD). Children were under 3 years of age at the beginning of the study and were then assessed at approximately 3, 5 and 9 years of age. Anderson *et al.* (2007) reported that 29% of the ASD group and less than 10% of the PDD-NOS and DD children remained non-verbal [i.e. using fewer than five words daily according to the Autism Diagnostic Interview – Revised (ADI-R)]. A key

contribution of this study was the item level reporting of the assessment data that provided more detail regarding language level than reporting standardised scores alone. Additionally, expressive language level was indicated by the Autism Diagnostic Observation Schedule (ADOS) module used (e.g. ADOS Module 3 'Complex sentences' and ADOS Module 2 'Sentences but not fluent'). The reporting of item level data is consistent with the approach adopted by Tager-Flusberg *et al.* (2009) and provides more clarity regarding communication outcomes using standardised assessments.

Magiati et al. (2011) and Norrelgen et al. (2014) also reported item level data from standardised assessments, in an attempt to characterise the spoken language outcomes for children with ASD in early intervention studies. Magiati et al. (2011) reported outcomes for 36 children, between two and five years after they commenced community based early intensive behavioural intervention. At initial testing (mean age 3 years 4 months) only 8% of the participants had functional phrase speech as assessed using the ADI-R, increasing to 36% at Time 2 (mean age 5 years 5 months). Norrelgen et al. (2014) used item level analyses of the Vineland Adaptive Behavior Scales-II (VABS-II) to document communication outcomes for 165 children with ASD aged 4-6.5 years from a population-based community sample. The authors reported that 25% of the participants in their study presented with minimal or no functional speech.

Through item level reporting and analyses using standardised tests, researchers have provided a clearer indication of spoken language level than could be provided by standard scores alone. Replication of such studies are important to gather descriptions from multiple settings, using large samples, and across populations, to gain a detailed understanding of communication outcomes for children with ASD. There is also a need to move beyond item level reporting and analyses of parent-reported measures (e.g. ADI-R, VABS-II) to include item scores from clinician administered direct assessments. Using a variety of assessments (i.e. parent/caregiver and clinician direct assessment) is important to develop a comprehensive profile of a child's communication skills (Lane et al. 2013; American Speech-Language-Hearing Association 2015). Therefore, the overall objective of this study was to document the proportion of children who were minimally verbal in a group of children with ASD who received a community-based early intervention programme. The specific aim was to analyse the proportion of children who were minimally verbal at entry and exit, using a combination of parent and clinician measures.

### Method

The study was independently reviewed and approved by the Griffith University Human Research Ethics Committee and the Research Advisory Group at the AEIOU Organisation. Signed informed consent was obtained from parents of participating children.

### Participants and setting

Participants were 246 children [202 male (82.1%), 44 female (17.9%)] who attended an ASD-specific centre-based early intervention programme in Australia between 2010 and 2015. The programme follows a comprehensive curriculum consistent with Australian Good Practice Guidelines (Prior et al. 2011) that uses a blend of strategies with theoretical underpinnings in behavioural and developmental approaches. Emphasis is on practices with emerging or higher levels of evidence as categorised by the National Autism Centre Standards Report (National Autism Center 2015), including the use of Augmentative and Alternative Communication systems (AAC) (Paynter et al. 2015). Individual Education Plans are developed for each child based on the organisation's autism-specific curriculum (Paynter et al. 2012). Teaching occurs within the context of classroom routines in an early learning context including circle and mat times, free play, small group activities and meal times (Paynter et al. 2012). The programme is delivered in a transdisciplinary team including teachers, speech pathologists, occupational therapists, behaviour therapists and paraprofessionals with training in early childhood in a ratio of 1:2 to 1:4 in a centre-based early learning ASD-specific setting. Refer to Paynter et al. (2015) for further information on this programme. Children attended the programme 15-25h per week with most attending five days per week for an average of 14 months (SD = 6.45) between intake and exit assessments. Programme eligibility included a community-based diagnosis of ASD (DSM-IV and DSM-5) by a medical practitioner

(paediatrician or child psychiatrist) or multidisciplinary team, and chronological age between 30 and 71 months (Paynter *et al.* 2015). Diagnosis was verified with the Social Communication Questionnaire (SCQ) using a cut-off of 11 as recommended in previous research with preschool age children (Lee *et al.* 2007), resulting in the exclusion of 18 participants from analyses (n = 228).

#### Measures

Communication outcomes included (a) ASD screening and diagnostic tools, (b) direct standardised assessment of the children's expressive language skills and (c) standardised parent-report assessment of children's expressive language skills in home and community settings. Clinician administered assessments were conducted by staff employed by the organisation with experience in assessing children with ASD, but who were not involved in the daily programme. These staff included the fourth author who is an experienced psychologist, and staff under her direct supervision with all assessors trained in test administration and engaging in regular supervision to ensure use of standard administration procedures as per the test manuals. For parent-report measures, parents/caregivers were instructed to respond based on their child's use of verbal communication only, excluding use of AAC.

AI. The SCQ (Rutter et al. 2003) is a parent/caregiver ASD screening checklist. We used Item I ('Is she/he now able to talk using short phrases or sentences?') as a measure of spoken language level.

A2. The ADOS (Lord et al. 2000) is a semistructured standardised assessment of communication, social interaction, play and restricted and repetitive behaviours (Lord et al. 2000). We used item AI of the coding scheme ('Overall level of Non-Echoed Spoken Language') to determine children's language level at entry and exit. Just under a third of the participants (n = 76) completed ADOS assessments at both entry and exit because of differences in data collection across centres and measures for documenting outcomes in this cohort.

B. The Mullen Scales of Early Learning (MSEL) (Mullen 1995) is a standardised assessment of developmental level of young children (Mullen 1995). Items are scored along a continuum from 0 to 5, 0 indicating an incorrect or absent response, and 5 (or the

highest score available) indicating full points were achieved. The total number of points available varies by item. We used the following 'Expressive Language' item scores to determine expressive language level: Item 11 ['Says first words', scoring (0) 0 words, (1) Says 1 word, (2) Says 2 to 7 words, (3) Says 8 words]; Item 17 ['Uses two-word phrases', scoring (1) Yes, (0) No]; Item 18 ['Picture Vocabulary', scoring (0) Names 0-4 pictures, (1) Names 5-10 pictures, (2) Names 11-14 pictures, (3) Names 15-16 pictures, (4) Names 17 pictures, (5) Names 18 'pictures'] and Item 22 ['Uses three- to four-word sentences', scoring (1) Yes, (0) No]. Only behaviours observed during direct assessment were given credit, and only children's verbal communication (i.e. no use of AAC) was scored.

C. The *VABS-II* (Sparrow *et al.* 2005) is a parent/caregiver form used to understand a child's adaptive behaviours. Items are rated as 2 = *usually*, I = *sometimes or partially* or 0 = *never* (Sparrow *et al.* 2005). We used the following 'Talking' item scores as per Norrelgen *et al.* 2014: Item 12 ['Names at least three objects (for example, bottle, dog, favourite toy, etc.)'] and Item 18 ["Uses phrases with a noun and a verb (for example, 'Katie stay'; 'Go home'; etc.)"].

## Results

Data screening was conducted to look for possible missing data; some measures were missing because of differences in the assessment battery across sites (ADOS), parent/caregiver checklists not being returned (usually for exit assessments), missed assessments because of scheduling constraints and a small number of children who left the programme prior to assessment; these are presented in Table I along with the children's chronological age at, and time between, assessments.

# Communication outcomes based on screening and diagnostic tools

As presented in Table 2, data derived from Item 1 of the SCQ ('Is she/he now able to talk using short phrases or sentences?') indicated that 62.5% of children were not talking in phrases/sentences at entry. At exit, this reduced to 32.1%, with a significant increase in the proportion of children using phrase speech over time,  $\chi^2$  (1) = 38.782, P < 0.001, OR = 1.95. However, the

Table I Children's chronological age at, and time between, assessments

			Entry					Exit			Time between	assessments
		n	Age	(month	s)		n	Age	(month	ıs)	(mon	ths)
	Valid	Missing	Median	Mean	SD	Valid	Missing	Median	Mean	SD	Mean	SD
SCQ	228	0	44.00	44.18	9.44	170	58	59.50	59.29	7.51	14.39	6.61
<b>ADOS</b>	122	106	42.00	42.53	8.89	82	146	57.00	56.68	16.21	14.13	6.11
MSEL	226	2	44.50	44.61	9.55	176	52	60.00	59.56	7.39	14.07	6.64
VABS	224	4	44.39	44.00	9.56	172	56	60.00	59.39	8.80	13.99	6.63

Table 2 Social Communication Questionnaire (SCQ) - Item 1

		Exit – 'using phr	ases or sentences'	
		No	Yes	Total n = 168
Entry – 'using phrases or sentences'	No	31.0% (52)	31.5% (53)	62.5% (105)
	Yes	1.2% (2)	36.3% (61)	37.5% (63)
Total		32.1% (54)	67.9% (114)	100.0% (168)

move towards the development of phrase speech was not uniform across the sample, with two children (1.2% of sample) reported to be speaking in phrases at entry but not at exit.

Children's scores on Item AI of the ADOS ('Overall level of Non-Echoed Spoken Language') at entry and exit are shown in Table 3. Of the 228 children, 76 had ADOS assessments at both time points and were included in this analysis [Entry:

Module I = 69; Module 2 = 7; Exit: Module I = 48; Module 2 = 27, missing = I,  $\chi^2$  (I) = I3.725, P < 0.001, OR = I.44]. We were interested in the percentage of children documented to be using less than 5 spontaneous and functional words/word approximations during the assessment (i.e. score of 3, 4 or 8; refer to Table 3 for definitions). Overall, 26.3% of children (I5.8% + I0.5%) used less than 5 functional words at their exit ADOS assessment

 Table 3
 Autism Diagnostic Observation Schedule (ADOS)

				Exit ADOS A I			
Score		0	ı	2	3	4/8	Total n = 76
Entry ADOS AI	0	32.9% (25)	1.3% (1)	0.0% (0)	0.0% (0)	0.0% (0)	34.2% (26)
,	1	9.2% (7)	2.6% (2)	3.9% (3)	0.0% (0)	0.0% (0)	15.8% (12)
	2	6.6% (5)	2.6% (2)	1.3% (1)	1.3% (1)	0.0% (0)	11.8% (9)
	3	2.6% (2)	7.9% (6)	0.0% (0)	9.2% (7)	1.3% (I)	21.1% (16)
	4/8	2.6% (2)	0.0% (0)	0.0% (0)	5.3% (4)	9.2% (7)	17.1% (13)
Total		53.9% (41)	14.5% (11)	5.3% (4)	15.8% (12)	10.5% (8)	100.0% (76)

*Note.* 0, regular use of utterances with two or more words; 1, occasional phrases only; mostly single words; 2, recognisable single words or word approximations only; must use at least five different words during ADOS evaluation; 3, at least one word or word approximation, but fewer than five words used during the ADOS-2 evaluation; 4/8, no words or word approximations (depending on ADOS Module 1 or 2).

compared with 38.2% at entry (21.1% + 17.1%), with a statistically significant increase in language level over time,  $\chi^2$  (16) = 84.153, P < .001, OR = 1.45.

# Communication outcomes based on standardised direct assessment

Four items of the MSEL Expressive Language Scale were used to examine changes in the children's spoken language skills. As per the assessment protocol adopted, only behaviours observed during assessment were scored. Table 4 presents the percentages of children who were using 0 words, 1 word, 2–7 words and 8 or more words as scored on Item 11 of the MSEL ('says first words'). The proportion of children using 0 or only 1 word reduced from 32.8% (31% + 1.8%) at entry, to 22.8% (20.5% + 2.3%) at exit, representing a significant increase in language level over time,  $\chi^2$  (16) = 84.153, P < 0.001, OR = 1.43.

As presented in Table 5, 57.2% of children were not using 'two word phrases' (Item 17) at entry, reducing to 36.4% at exit, with a significant increase in language level between entry and exit,  $\chi^2$  (1) = 49.128, P < 0.001, OR = 1.57.

Table 6 shows the percentage of children who accurately labelled 0, 5–10, 11–14, 15–16, 17 and 18 pictures correctly during the Picture Vocabulary task (Item 18) of the MSEL. As shown, the majority of children were not yet labelling pictures at entry (67.1%). Of the 67.1% of children who were not labelling pictures at entry, 16.8% labelled 18 pictures at exit, while 37% still could not label any pictures at exit, representing a significant increase in language ability from entry to exit,  $\chi^2$  (20) = 61.532, P < 0.001, OR = 1.76.

As presented in Table 7, 68.6% of children were not 'using three-to-four word sentences' (Item 22) at entry, reducing to 40.6% at exit, indicating a statistically significant decrease in proportion over time,  $\chi^2$  (I) = 44.583, P < 0.00I, OR = 1.63.

# Communication outcomes based on standardised parent report

Two items on the VABS-II Talking Domain were used to examine changes in the children's spoken language skills as indicated by parent report. We were interested in the percentage of children documented to 'name(s) at least three objects' as indicated by Item 12 of the VABS-II, and not consistently use 'phrases

Table 4 Mullen Scales of Early Learning (MSEL) – Expressive Language Item 11

			Exit – 'Sa	ys first words'		
Score		0 words	l word	2-7 words	8 words	Total n = 171
Entry – 'Says first words'	0 words	15.8% (27)	1.8% (3)	3.5% (6)	9.9% (17)	31.0% (53)
	I word	.6% (1)	0.0% (0)	0.0% (0)	1.2% (2)	1.8% (3)
	2-7 words	2.3% (4)	.6% (1)	3.5% (6)	8.2% (14)	14.6% (25)
	8 words	1.8% (3)	0.0% (0)	4.1% (7)	46.8% (80)	52.6% (90)
Total		20.5% (35)	2.3% (4)	11.1% (19)	66.1% (113)	100.0% (171)

 Table 5
 Mullen Scales of Early Learning (MSEL) – Expressive Language Item 17

		Exit – 'Uses tw	vo-word phrases'	
		No	Yes	Total n = 173
Entry – 'Uses two-word phrases'	No	33.5% (58)	23.7% (41)	57.2% (99)
	Yes	2.9% (5)	39.9% (69)	42.8% (74)
Total		36.4% (63)	63.6% (110)	100.0% (173)

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Table 6 Mullen Scales of Early Learning (MSEL) – Expressive Language Item 18

			ı	Exit – Pictur	e vocabular	у		
		0–4 pictures	5–10 pictures	- 4 pictures	15–16 pictures	17 pictures	18 pictures	Total n = 173
Entry –	0-4 pictures	37.0% (64)	5.8% (10)	6.4% (11)	1.2% (2)	0.0% (0)	16.8% (29)	67.1% (116)
Picture	5-10 pictures	.6% (I)	.6% (I)	1.7% (3)	0.6% (1)	0.0% (0)	3.5% (6)	6.9% (12)
Vocabulary	II-I4 pictures	0.0% (0)	0.0% (0)	.6% (1)	0.0% (0)	0.0% (0)	5.2% (9)	5.8% (10)
,	15–16 pictures	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	.6% (1)	.6% (1)
	17 pictures	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	.6% (I)	.6% (1)
	18 pictures	.6% (1)	1.2% (2)	1.2% (2)	.6% (1)	0.0% (0)	15.6% (27)	19.1% (33)
Total	•	38.2% (66)	7.5% (13)	9.8% (17)	2.3% (4)	0.0% (0)	42.2% (73)	100.0% (173)

Table 7 Mullen Scales of Early Learning (MSEL) – Expressive Language Item 22

		Exit – 'Uses three- to	four- word sentences'	
		No	Yes	Total n = 175
Entry – 'Uses three- to four- word sentences'	No	40.6% (71)	28.0% (49)	68.6% (120)
·	Yes	1.7% (3)	29.7% (52)	31.4% (55)
Total		42.3% (74)	57.7% (101)	100.0% (175)

with a noun and a verb' as indicated by Item 18. We did not give full credit to children who were scored a '1' indicating they 'sometimes or partially' displayed this skill (i.e. score 0 or 1 rated as minimally verbal). As shown in Table 8, 52.4% of children were not consistently naming at least three objects (Item 12) at entry, reducing to 29.5% of children at exit, with a significant increase in language level over time,  $\chi^2$  (4) = 61.009, P < 0.001, OR = 1.78.

Table 9 shows the number of children reported to be using 'phrases with a noun and a verb' (Item 18) as indicated by the VABS-II. In total, 73.5% of children were not consistently using two word phrases at entry, reducing to 43.2% of children at exit, with a significant increase in language level between entry and exit,  $\chi^2$  (4) = 62.55, P < 0.001, OR = 1.70.

We computed scores by combining responses across these two items (12 and 18) to allow comparison across studies using Norrelgen *et al.*'s (2014) classification of minimally verbal as 'using at least three words but never or only sometimes/partially two-word phrases', and non-verbal as 'using fewer

than three words' (p.3). As shown in Table 10, 53.5% of children were using fewer than three words at entry, and a further 20.3% were using more than three words but rarely two word phrases. At exit, 29.4% of children were still using fewer than three words, and a further 15% were using three words, but not yet using two word phrases, representing a significant increase in language level from entry to exit,  $\chi^2$  (4) = 65.322, P < 0.001, OR = 1.66 (collapsed non-verbal and minimally verbal).

### Comparing parent and clinician ratings

To examine the extent to which different measures of children's spoken language abilities yielded similar results, we compared the scores for each child on relevant items on the parent-completed SCQ (Item I) and VABS-II (Item I8), with those on the clinician-administered MSEL (Item I7). To allow for comparisons across measures, and to ensure consistency with our previous analyses, we categorised children who received a '2' on the VABS-

 Table 8
 The Vineland Adaptive Behavior Scales - 2 and Edition (VABS-II) - Talking Item 12

		Exit – 'name(s) at	least three objects'	_
		No	Yes	Total n = 187
Entry – 'name(s) at least three objects'	No	51.0% (50)	49.0% (48)	52.4% (98)
,	Yes	5.6% (5)	94.4% (84)	47.6% (89)
Total		29.4% (55)	70.6% (132)	100% (187)

**Table 9** The Vineland Adaptive Behavior Scales – 2<sup>nd</sup> Edition (VABS-II) – Talking Item 18

		Exit – using 'phrases v	with a noun and a verb'	
		No	Yes	Total n = 185
Entry – using 'phrases with a noun and a verb'	No	58.1% (79)	41.9% (57)	73.5% (136)
	Yes	2.0% (1)	98.0% (48)	26.5% (49)
Total		43.2% (80)	56.8% (105)	100% (185)

II as having speech, and 'o' ('never') or '1' ('sometimes/partially') as not. We combined scores from both entry and exit assessments and found 77.8% agreement across all three measures [49.8% of the time all measures agreed 'yes' (to speech) and 50.2% agreed 'no']. We also found inconsistent agreement across the three measures (i.e. two agreed, one did not) on 22.2% of occasions. In these cases, the assessment which was different (i.e. different to response on both other measures) was SCQ in 23.9%, MSEL in 42.3% and VABS in 33.8%.

#### Discussion

We aimed to investigate the proportion of children who were minimally verbal in a group of children who

received a community-based early intervention programme. Overall, 26.3% of children exited the programme with fewer than five spoken words/phrases used spontaneously and communicatively as indicated by the ADOS (Kasari et al. 2013). We found that while just under half of the children in our study progressed from having minimal speech at entry (e.g. 'says first words' and 'uses phrases with a noun and a verb') to some speech (e.g. using phrases/sentences on the MSEL and SCQ, and using more than five spontaneous and functional words/word approximations on the ADOS) at exit, more than half of the children who entered the programme with a 'very small repertoire of spoken words', exited the programme with similar language levels. Consistent with previous research, we also

Table 10 Minimally verbal status using combined VABS-II Item 12 and Item 18

			Exit – Verbal status	5	
		Non-verbal	Minimally verbal	Phrase speech	Total n = 187
Entry Verbal status	Non-verbal	26.7% (50)	10.2% (19)	16.6% (31)	53.5% (100)
•	Minimally verbal	2.1% (4)	4.3% (8)	13.9% (26)	20.3% (38)
	Phrase speech	0.5% (1)	0.5% (1)	25.1% (47)	26.2% (49)
Total	·	29.4% (55)	15.0% (28)	55.6% (104)	100.0% (187)

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found that a small percentage of children (1.2%–4.7% depending on item used) regressed in their language use, although our figure was less than previously reported (Lord *et al.* 2004). However, previous studies have also included loss of vocalisations and fluctuating word loss in their reports, which was beyond the scope of our analysis (Lord *et al.* 2004).

Differences in defining minimally verbal, measures used to operationalise this, age of participants and sampling approaches all impact on outcome comparison across studies (Jonsdottir et al. 2007; Norrelgen et al. 2014). Tager-Flusberg et al. (2009) and Kasari et al. (2013) highlighted the need to look at finer-grained approaches to measuring communication outcomes in order to provide specific detail regarding overall language level. In addition, it is important that our definition of minimally verbal aligns with our measurement. Consistent with previous studies (Anderson et al. 2007; Magiati et al. 2011; Norrelgen et al. 2014), we took this approach by looking at individual test scores, rather than reporting overall standardised scores. We found significant changes in language level over time as assessed by relevant items from diagnostic and screenings tools (SCQ and ADOS). In addition, we found significant changes in language when reporting on specific items from direct assessments (MSEL). While no measure can replace the gold standard of language sampling and analysis of spoken language in natural environments to assess language use (Kasari et al. 2013), standardised assessments offer a consistent testing context, and item level reporting as used in this study (e.g. SCQ, MSEL and VABS-II) is readily available and interpretable by caregivers, clinicians and educators. Based on our definition of minimally verbal and outcome measures used, we found that while there was a significant change in language level following early intervention, a substantial number of children remained without spontaneous and functional language at exit of the programme, and a small percentage regressed in their spoken language.

Our finding that 26.3% of the children in our study did not develop functional language (ADOS) was slightly lower than reported in some earlier studies (Kjelgaard & Tager-Flusberg 2001; Anderson *et al.* 2007; Magiati *et al.* 2011). These may be attributed to differences in definition, method, participant age and other sample characteristics. Our findings from the ADOS are consistent with those of Norrelgen *et al.* 

(2014), who documented that 25% of their participants were described as being non- or minimally verbal at 6.5 years as indicated by the VABS-II. These children were, on average, approximately 18 months older than our sample. However, our finding that 29.4% of children in our study met Norrelgen et al. (2014) criteria for nonverbal and 15% met their criteria for minimally verbal were considerably higher. In the Norrelgen et al. (2014) and our study, children had received approximately one to two years of intervention. When considering change in proportion over time, it is important to note that children were on average 4.5 years of age in both studies and that magnitude of change may be greater had the studies included children who commenced intervention earlier.

An important contribution of the current study was the use of item level analysis from direct assessment, in addition to parent/caregiver report. We did find, however, relatively high reliability between parent/caregiver report and clinician administered assessments, indicating that all methods are useful for measuring and documenting language level. This is consistent with previous research in adaptive behaviour comparing caregiver and parent ratings on the VABS-II (Lane *et al.* 2013). However, it is important to note subtle differences between measures (e.g. 'says first words' on MSEL versus 'names at least three objects' on VABS-II), which could lead to differences in scoring, depending on the child's use of nouns in his or her early spoken vocabulary. Furthermore, we propose that reporting item scores, rather than overall standard scores or age equivalents, yielded a clearer picture of children's spoken language levels with regards to the number of words used functionally, and the complexity of their language use (i.e. single words and phrases/sentences).

While there are inherent problems with the sole reliance on standardised assessments to document communication outcomes for children with minimal spoken language (e.g. placing demands on children to understand and respond to questioning and, floor effects because of difficulties performing under strict standardised conditions) (Abbeduto *et al.* 2011; Kasari *et al.* 2013), our results suggest that item level analysis can provide further detail regarding specific language level, and we recommend this fine-grained data be reported in intervention studies (Anderson *et al.* 2007; Magiati *et al.* 2011). This would help us understand the individual variability in communication outcomes

and provide detailed insight into specific language level and use. Furthermore, using multi-informant measures also provides information regarding individual language level across settings and contexts (Abbeduto *et al.* 2011).

The assessment tools reported in our study are commonly used in intervention research involving children with ASD (Trembath et al. 2016) and have been designed for use in both clinical and research settings. Accordingly, we advocate for the consistent use of tools such as these, where possible, across settings to allow for tracking and comparison of children's outcomes. However, we acknowledge that the cost of administering these tools and expertise required likely act as barriers to their widespread use in community based early intervention services. Fortunately, service providers routinely document children's development in rich detail through assessment reports, file notes, staff-parent correspondence, children's work portfolios and educational planning documents. Increasingly, this information is being generated and stored electronically, creating the opportunity for sharing and analysis of de-identified data. The challenge is to develop and adopt a set of minimum standards for the collection and reporting of spoken language information (e.g. spoken language benchmarks; Tager-flusberg et al. 2009), which can be accurately interpreted and easily applied by clinicians, parents and educators working to support the learning and development of children with ASD.

The findings of our study need to be considered with respect to several limitations. As with previous studies, population sampling, the intervention programme children receive and the outcome measures employed impact on the proportion of children found to be minimally verbal. It is likely that some high functioning children will not yet be diagnosed by preschool age (Anderson et al. 2007; Centers for Disease Control and Prevention 2014), and therefore may not have been included in our sample. Likewise, even if diagnosed, these children may not present for early intervention because of displaying higher levels of adaptive behaviour. That said, the ASD-specific centre-based early intervention programme caters for children with a range of abilities and is the single largest ASD early intervention provider in the Queensland region, suggesting that it likely captures a broad range of abilities. Ideally,

future research would include population level data through health or education records; however, such data are not currently available in Australia; thus, our approach yields an estimate based on available data.

A further limitation of this study is the focus on assessing spoken language only. As mentioned, the programme the children accessed supported the use of AAC, and it is therefore possible that some children who used AAC in the programme may have functional communication in other modalities, which was not captured in the standardised assessments. As the parents in our study were instructed only to complete reports on communication based on spoken language, it is possible that communication conveyed via other modalities was not captured. The proportion of children who were able to use phrases or functional communication using AAC is an important question, but one that could not be answered in this study. Thus, in future research, collection of data on the use of AAC including functional communication would be of value in characterising the full spectrum of communication outcomes.

### Future research directions

Our findings point to the need for a consistent definition and protocol for assessing communication outcomes in children with ASD with little or no functional speech, for example language sampling to gain further insight into an individual's overall communication repertoire (Kasari et al. 2013). We encourage clinicians and researchers to specify communication outcomes and report individual outcomes in their data. We stress the need to pay closer attention to how we talk about this group of individuals presenting with little or no functional speech and how we operationalise this for research purposes. Ultimately, we advocate movement towards a uniform definition for research purposes, including the reporting of standard measures. Given that standardised assessments such as those used in this study are frequently used in research, they provide an immediate avenue through which researchers can report finer detail, and authors of previously published research can revisit their data and publish their findings so that we can benefit from information already collected. In addition, given the use of AAC with individuals with complex communication needs, it is important to report on

AAC use in addition to spoken language (e.g. number of spontaneous words/phrases/sentences used functionally using alternate communication systems). As there is increasing awareness of, and evidence supporting the use of AAC with individuals with ASD and minimal speech, it is important that we recognise and acknowledge the contribution of these systems for enhancing the communicative competence for individuals with little or no functional speech, by reporting on the use of these programmes as part of an individual's overall communication repertoire (Goods et al. 2013; Kasari et al. 2014). Finally, in addition to analysing how children with ASD communicate (i.e. spoken language, AAC and combination of modalities), future research should also evaluate why children with ASD communicate and how effectively and functionally they use their communication skills to interact and learn from their environment.

### Conclusion

Of the participants in our study who entered the programme as minimally verbal, more than half continued to present with significant communication needs at exit of the programme with regards to spoken language. Nevertheless, of those who did progress from initially a very small repertoire of spoken words or fixed phrases to having some speech, a number of individuals noticeably progressed in their language skills, highlighting considerable differences in language trajectories irrespective of initial language level at entry. The findings of this research indicate that standardised assessments can be used to document communication outcomes for children with ASD with little or no functional speech, but that more attention should be given to particular items administered rather than solely standard scores. We encourage other researchers to report on item level scores in order to contribute to our understanding of the communication profiles of individuals with ASD and their response to intervention. In addition to reporting spoken language outcomes for individuals with ASD, we need to recognise the importance of documenting AAC use. While spoken language constitutes an important part of the communication process, it is important that we are also evaluating other important communication skills including, non-verbal and augmentative and alternative communication.

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Appendix: Minimally verbal terminology and definitions

V. Rose et al. • Proportion of minimally verbal children with ASD

Relevant outcome measure used (if applicable) Receptive and Expressive Language mean scores. while category 3 defines verbal status' (p. 1365) (2) words but no phrases; no functional use of or stereotyped speech, but use of speech on a that, on a daily basis, involves phrases of three words or more that at least sometimes include ADI-R – classify language based on AI 'overall spontaneous, echoed or stereotyped language a verb and is comprehensible to other people. Not applicable. However discussion regarding total and/or no use of speech on a daily basis; daily basis with at least five different words in the last months; (3) phrases; functional use of VABS-II- Expressive Language age equivalent level of language' '(1) fewer than five words three word phrases in spontaneous, echoed Categories I and 2 define non-verbal status, Transcription of Natural Language Sample – both spoken and Speech Generator Device-Peabody Picture Vocabulary Test (PPVT-4) scores, as well as individual items from the Talking' domain to classify language level. Expressive Language mean scores. MSEL oest ways for capturing language level in transcribed and coded, and mode noted. produced spontaneous utterances were **Test of Early Language Development** The Reynell Developmental Language Scales - Verbal Comprehension and ninimally verbal children with ASD. but never or only sometimes/partially two-word words by parent and teacher report and during corresponding to below 24 months' (p. 3)'Nonresearchers may want to impose a quantitative Minimally verbal' 'fewer than 20 spontaneous definition for this population (e.g. fewer than Minimally verbal' 'using at least three words verbal" using fewer than three-words and an the baseline or entry assessments' (p. 1051) spontaneous, functional and communicative different words used during the 20 minutes Minimally verbal' 'Although from a clinical' of words used does not matter that much, educational perspective, the exact number phrases and an expressive age equivalent NLS [natural language sample]' (p. 637) Minimally verbal' 'used less than 10 20 functional words)' (p. 2). non-verbal Definition Communication interventions for minimally who do not develop phrase speech in the stability and change during the preschool aged child with autism spectrum disorder Children with autism spectrum disorders Preschool based JASPER intervention in verbal children with autism: a sequential minimally verbal children with autism: Assessing the minimally verbal school-Follow-up of children diagnosed with multiple assignment randomized trial pervasive developmental disorders: preschool years pilot RCT Title years (Norrelgen et al. 2014) (Jonsdottir et al. 2007) (Goods et al. 2013) (Kasari et al. 2013) (Kasari et al. 2014) Author/s

(Continued)			
Author/s	Title	Definition	Relevant outcome measure used (if applicable)
(Paul et al. 2013)	Comparing spoken language treatments for minimally verbal pre-schoolers with autism spectrum disorders	expressive age equivalent corresponding to below 15 months' (p. 3) 'Minimally verbal' 'spontaneous expressive vocabulary by parent report of fewer than 15 words' (p. 420).	Communication and Symbolic Behavior Scales – Caregiver QuestionnaireCommunication and Symbolic Behavior Scales-Behavioral Observation VABS-II – expressive language age equivalent.
(Woynaroski et al. 2015)	Atypical cross-modal profiles and longitudinal associations between vocabulary scores in initially minimally verbal children with ASD	'Minimally verbal' and 'preverbal' '(c) were reported to say no more than 20 different words according to a parent report on the MacArthur-Bates Communicative Development Inventories: Words and Gestures Checklist (MCDI) [Fenson et al., 2003]; and (d) produced no more than five different word roots during and in paging council, '(c) 2).	Composite scores.  MacArthur-Bates Communicative Development Inventories: Words and Gestures Checklist (MCDI) - Used raw scores to enable maximum sample size and appropriate imputation, and age equivalency scores.
(Yoder & Stone 2006)	A randomized comparison of the effect of two prelinguistic communication interventions on the acquisition of spoken communication in preschoolers with ASD.	a 19-11111 anguage sample (p. 3) 'Non-verbal' or 'low verbal''Fewer than 20 different words used cumulatively during three communication samples' (p. 700).	Semi structured free-play with examiner (SFPE) Developmental Play Assessment Turn-taking assessment
(Yoder et al. 2014)	Value-added predictors of expressive and receptive language growth in initially non-verbal pre-schoolers with autism spectrum disorders.	'Non-verbal' '(c) were reported to say no more than 20 different words according to parent report on the MacArthur Bates Communicative Development Inventories: Words and Gestures checklist (Fenson et al. 2007); and (d) produced no more than five different word roots during a 15-minute language sample' (p. 3).	MacArthur Communicative Development Inventory-Words and Gestures Form (MCDI) – Raw scoresCommunication and Symbolic Behavior Scales – Developmental Profile Behavior Sample (CSBS) – weighted raw scoresUnstructured Communication Sample