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**Title**

A twelve-month follow-up of an information communication technology delivered intervention for children with autism spectrum disorder living in regional Australia.

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## **Compliance with Ethical Standards**

### ***Funding***

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### ***Conflict of Interest***

The application described in this paper is available online through the Apple App store. The authors (and funders) have no affiliation with the application or its developers and will not receive, or have previously received, any royalties from sales. The authors declare no other conflicts of interest.

### ***Informed consent***

Informed consent was obtained from all individual participants included in the study

## **Abstract**

This study investigated the long-term follow-up of an information communication technology based intervention, the Therapeutic Outcomes By You application, for children with autism spectrum disorder living in regional Australia. Fifteen participants who completed a three-month randomised controlled trial of the Therapeutic Outcomes By You were assessed at least 12 months post-intervention to determine the maintenance or continued improvement of their language and social communication skills. Findings demonstrate the receptive language, social skills, pragmatic language and playfulness of children with autism spectrum disorder improved during the three-month intervention period and were maintained at least 12 months after ceasing the Therapeutic Outcomes By You app intervention.

**Keywords:** Information technology, early intervention, parent training

## **What this paper adds**

This paper is one of the few studies that investigates the long-term follow-up of an information communication technology based intervention for children with autism spectrum disorder. This study uses standardised assessment tools and appropriate statistical evaluations to support its conclusions. The findings demonstrate the receptive language, social skills, pragmatic language and playfulness of 15 children with ASD who participated in this study improved during the three-month intervention period and were maintained at least 12 months after ceasing the TOBY app intervention. In addition to using standardised outcome instruments to measure the developmental outcomes of the children who participated in study 12 months after the intervention, the study sought to seek parents' opinions on the continued

use of the app and the maintenance of skills learnt while using the TOBY app. Parents reported a number of reasons as to why they had stopped using the application since the trial ceased, with a lack of time and a loss of interest from their child in the application cited as the main reasons.

## **1.0 Introduction**

Autism spectrum disorder (ASD) is a pervasive life-long neurodevelopmental condition characterised by impairments in social communication and social interaction across multiple contexts, and the presence of restricted and repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013). Impairments in these areas can manifest in several ways, including but not limited to: a high sensitivity to environmental changes, challenges developing age-appropriate friendships, difficulties with sensory processing, and deficits in interpreting non-verbal communication (American Psychiatric Association, 2013).

Early Intensive Behavioural Interventions (EIBI) have been reported as effective in reducing the core features of ASD and have been mooted as long-term cost-effective interventions due to the improvements in skills resulting in a reduced need for programs and supports as the child matures (Dawson et al., 2010; Matson & Konst, 2013; Oono, Honey, & McConachie, 2013; Ramdoss et al., 2012). However, the overall cost-effectiveness of EIBI relies on the assumption that the child maintains the skills learnt during the intervention period and beyond. Moreover, the long term maintenance of skill acquisition in EIBI intervention studies for children with ASD is seldom investigated (Matson & Konst, 2013).

Common EIBI interventions cited in the literature include the Early Start Denver Model, ABA, Discrete Trial Training, and Pivotal Response Training (Dawson et al., 2010; Prior & Roberts, 2012b; Thomson, Martin, Arnal, Fazzio, & Yu, 2009). All of these interventions require considerable therapy time (in the form of highly trained personnel) and financial resources (Whalen, Liden, Ingersoll, Dallaire, & Liden, 2006). Current best practice guidelines for EIBI require the child to receive at least 25 hours of EIBI per week to improve skills in imitation, joint attention, play skills, and both receptive and expressive language (Prior & Roberts, 2012b). Despite its long-term benefit, this level of intensity often places

significant short-term financial and psychological strain on the family; a consideration that is even more pronounced when families need to travel long distances to access services (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; McAuliffe, Vaz, Falkmer, & Cordier, 2016; Prior & Roberts, 2012a; Sim et al., 2017).

With such a high amount of resources required to implement EIBI effectively, innovative models of service delivery for interventions, such as parent-mediated, telehealth or ICT-based delivered interventions may hold the key to augment current services. These type of delivery methods may have the potential to decrease access barriers and increase dosage for children with ASD, while not compromising effective intervention delivery, particularly for families living in regional and remote communities. Further, given the high financial, psycho-emotional and service access challenges experienced by families of children with ASD living in regional areas, there is a need to assess the long-term impact of EIBI to ensure the intervention has a long-term benefit for the child (Matson & Konst, 2013).

The United Kingdom Medical Research Council (UKMRC) framework for the development of complex intervention recommends long-term follow-up of participants to determine if short-term changes persist and while these studies are uncommon, they are highly informative (Campbell et al., 2000; Craig et al., 2008). Further, if interventions do not demonstrate maintenance of skills, then time and resources invested in teaching skills or implementing interventions with poor long-term efficacy could potentially be squandered (Alper & Raharinirina, 2006).

Preliminary evidence supporting the efficacy of information communication technology (ICT) based interventions for children with ASD is continuing to develop with robust randomised controlled trials and systematic reviews supporting their use to improve social, emotional and communication skills ( [REDACTED] ); Ramdoss

et al., 2011; Ramdoss et al., 2012; Wainer & Ingersoll, 2011; Whitehouse et al., 2017). While there have been some small studies suggesting the maintenance of skills in augmentative and alternative communication devices for children with ASD, there are few larger studies that have included long-term follow-up in their design to assess the maintenance of skills in ICT-based interventions targeting social communication skills (Achmadi et al., 2014; McLay et al., 2015). The Therapeutic Outcomes By You application (TOBY app) is an early intervention iPad application and intervention tool based on Applied Behavioural Analysis (ABA) principles and EIBI guidelines, which was specially developed by a multidisciplinary team comprising of psychologists, speech pathologists and computer scientists for children aged two to six with ASD (Moore et al., 2015; Parsons et al., 2018; Venkatesh, Phung, Duong, Greenhill, & Adams, 2013).

The TOBY app targets the following skills areas: 1) receptive and expressive language; 2) sensory awareness; and 3) imitation and social interaction skills, such as joint attention and nonverbal gestures (Moore et al., 2015; Parsons et al., 2018). The TOBY app was designed to supplement existing therapy, not replace it. The application is a low-cost intervention and can be easily accessed through the Apple App store (AUD\$25.99) (Moore et al., 2015). Although not designed for this purpose, parents can use the TOBY app at home independent of any clinician input. The developers of the TOBY app claim its uniqueness is in how the intervention teaches a parent how to teach the child (Venkatesh et al., 2013).

One pilot study and two RCTs have evaluated the effectiveness of the TOBY app to date. The pilot study by Moore et al. (2015) reported that the TOBY app delivers reliable and accurate feedback, with the difficulty level being appropriately matched to the child's abilities. In their RCT, Whitehouse et al. (2017) demonstrated the effectiveness of the TOBY app in improving fine motor skills and visual perception skills; however, concluded the TOBY app does not reduce autism symptom severity levels in children aged two to six. The



second RCT by [REDACTED], from which the participants from this study were recruited, investigated the effectiveness of the TOBY app for children with ASD with a developmental age of two to six years who live in regional areas. Parents in this RCT were instructed to use the applications for 20 minutes per day at a time convenient to the family. Parents in the intervention group were provided with an iPad that had the application already loaded, and were given one-hour training by the researchers (occupational therapists and psychologists) on how to navigate and use the intervention. The intervention provided clear instructions to parents on how to implement the entire program with their child (Venkatesh et al., 2013). The therapy-as-usual group were asked not to download the TOBY app but were still able to receive their community-based therapy that they were accessing [REDACTED].

The authors reported statistically significant improvements in expressive language in children with ASD between the intervention group, who used the TOBY app 20 minutes per day for three months in addition to therapy-as-usual, and the control group who received therapy-as-usual without TOBY app use. Furthermore, improvements in receptive language, pragmatic language and social communication skills were detected within the intervention group participants ( $n = 59$ ) when measured pre-post over three months, suggesting skill acquisition ([REDACTED]). Although findings from the RCT effectiveness studies provide limited evidence the TOBY app is an effective intervention to improve the receptive language, social communication, fine motor and visual perception skill in children with ASD immediately post-intervention, a long-term follow-up study with participants to investigate the maintenance of these skills following use of the TOBY app has not yet been conducted.

To date, there is no evidence of maintenance of skills post using the TOBY app. Previous studies have reported the maintenance of skills in children with ASD following psychosocial interventions similar to those taught in the TOBY app, such as social and

language skills (Jones, Carr, & Feeley, 2006; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Wert & Neisworth, 2003). In a systematic review investigating the quality of behaviourally-based interventions to improve social interaction skills for a child with ASD, Camargo et al. (2014) reported that of 15 studies investigating the maintenance of social interaction skills in children with ASD, 13 studies showed children retained at least one of the intervention's target skills. Additionally, improved maintenance of learnt skills is achieved if the intervention is implemented in the context where the child will use the skill (Camargo et al., 2014). However, there are no studies to these author's knowledge that have investigated the maintenance of psychosocial skills following an ICT-based intervention in children with ASD living in regional areas.

This paper aims to report on a follow-up study of children with ASD living in regional Australia who used the TOBY app for three months in the RCT by [REDACTED] to determine if participants maintained or continued to improve their language and social communication skills after at least 12 months post-intervention. The study also aimed to explain the maintenance of skills and ongoing use of the TOBY app from the perspectives of the parents who participated in the RCT.

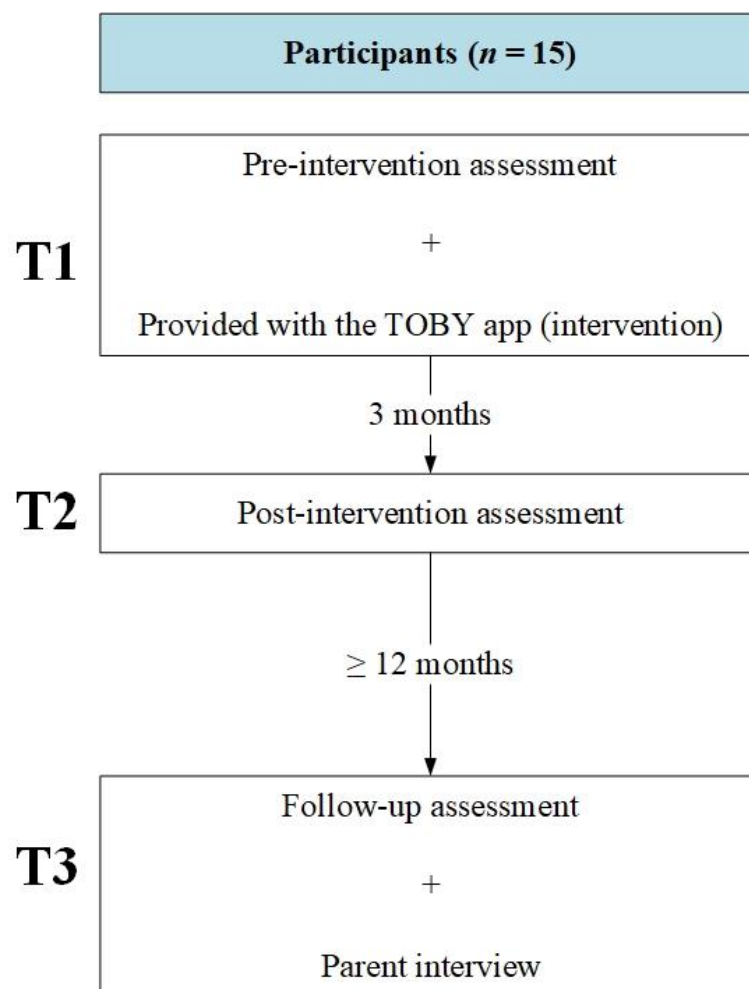
## **2.0 Methods**

### **2.1 Study Design**

This study used a single-site cohort design, with data collected at baseline (T1), post-intervention (T2) and follow-up at 12 months post-intervention (T3) (see Figure 1).

Participants were sampled from a larger sample who participated in an effectiveness study using an RCT design and had used the TOBY app for a minimum of three months [REDACTED]. We used purposive sampling to recruit participants from the RCT trial into this study to ensure maximum variation. Participants were invited based on recorded app use from

the lowest, middle, and highest segments from the RCT study across the duration of the study. The rationale was to gather data from participants with varying levels of engagement in the RCT with the aim of obtaining a representative sample to increase the generalisation of findings. Back-end server data automatically generated during app use were accessed and analysed as an objective measurement of usage. Usage was measured as a summation of participant ranking based on three components: 1) time on the app; 2) number of items attempted; and 3) number of items completed. Fifteen families with a child with ASD from the RCT agreed to participate in this study.



**Figure 1.** Outline of study procedure

## 2.2 Participants

Nineteen participants were invited to participate in the follow-up assessment. Four parents declined to participate. Thus, 15 parents and their children were included in the study. All parents who answered the open-ended questions in the follow-up study were mothers. Refer to Table 1 for the demographic information of the participants.

**Table 1.** Child and family characteristics at the 12-month follow-up time point

Participant Characteristics		Follow-up ( <i>n</i> =15)
Child Age in months	Mean (SD)	79.07 (22.33)
Child Gender	Male	11 (73.3%)
	Female	4 (26.3%)
Number of Children with ASD	1	12 (80.0%)
	2 or more	3 (20.0%)
Maternal Education	Diploma or Below	11 (73.3%)
	Bachelor Degree or higher	4 (26.7%)
Paternal Education	Diploma or Below	12 (80.0%)
	Bachelor Degree or higher	3 (20.0%)
Population density of area*	Inner Regional	13 (86.7)
	Outer Regional	2 (13.3%)
	Remote	0 (0%)
	Very Remote	0 (0%)
SEIFA Decile	Mean (SD)	6.53 (1.68)

*Note.* \*Based on the Australian standard geographical classification system (Australian Bureau of Statistics, 2011). The categories include major cities, inner regional, outer regional, remote, and very remote and are based on a number of variables including population size and distance by road to service centres.

SEIFA: Socio-economic index for areas

### **2.2.1 Inclusion and exclusion criteria**

All children in the study had a diagnosis of ASD as determined by a team of qualified health professionals using the Diagnosis and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). The children had a developmental age between two and six years and resided in areas outside of major cities in Western Australia as defined by the Australian Standard Geographical Classification System (Australian Bureau of Statistics, 2011). Participants were recruited through key ASD service providers including paediatricians, general practitioners (GPs), allied health clinicians (e.g., speech pathologist, occupational therapists, psychologists), parent support groups, community forums, media advertisements and snowballing techniques from the south-west region of Western Australia. Children with existing comorbidities commonly occurring with ASD (e.g., anxiety, attention deficit hyperactivity disorder) were included provided ASD was their primary diagnosis. If the parent consented, a face-to-face assessment was arranged at the convenience of the parents for the long-term follow-up. Informed written consent was obtained from all participants at the follow-up assessment. All assessments for the long-term follow-up were completed in the participants' homes.

Children were excluded from the study if they had a physical disability that prevented them from engaging in the recommended 20 minutes of therapy per day with the TOBY app. Further, children were excluded from the study if they had non-idiopathic cases of ASD including genetic disorders, such as Rett's syndrome and Fragile X syndrome (Luyster, Kadlec, Carter, & Tager-Flusberg, 2008). Informed consent was obtained prior to participation in the study. Ethical approval was obtained from the [REDACTED]

[REDACTED].

### **2.2.2 Demographic Information**

Demographic information was collected from all participants for: 1) child age; 2) child gender; 3) maternal education; 4) paternal education; and 5) regionality. Socioeconomic status (SES) was determined using the Socio-Economic Index for Areas (SEIFA) deciles. The SEIFA deciles are developed by the Australian Bureau of Statistics to rank areas according to their relative socio-economic advantage and disadvantage based on information from a five-yearly Census (Australian Bureau of Statistics, 2011). The SEIFA deciles are represented using a ten-point numerical scale, with a higher SEIFA score representing a higher SES status. Pink (2011) reports that a score of 1 to 3 reflects low SES, with 4 to 10 representing medium to high SES.

To define regionality, the Australian Geographical Classification System (AGCS) was used. The AGCS divides Australia into broad regions for comparative statistical purposes (Australian Bureau of Statistics, 2011). The ASGC remoteness structure is classified into five remoteness areas (RAs) (Australian Bureau of Statistics, 2011). The categories include: 1) major cities; 2) inner regional; 3) outer regional; 4) remote; and 5) very remote. RAs are based on road distances to the nearest service centres and average scores are calculated using the Accessibility/Remoteness Index of Australia (ARIA +) grid, which is a one square kilometre grid covering all of Australia (Australian Bureau of Statistics, 2011; McAuliffe et al., 2016).

## **2.3 Instruments**

A series of standardised repeated measures were administered at baseline (T1), post-test (T2) and at follow-up (T3) to assess the effectiveness of the TOBY app. These measures included: 1) Mullen Scales of Early Learning (MSEL) (Mullen, 1995); 2) Symbolic Play Test (SPT) (Lowe & Costello, 1988); and 3) Communication and Symbolic Behavior Scales

(CSBS) (Wetherby & Prizant, 2002). Additionally, a 20-minute video of spontaneous interaction with a neuro-typical person was obtained at all data collection time points. Two standardised observation measures were used to analyse the video data; 1) Pragmatic Observation Measure (POM); and 2) Test of Playfulness (ToP) (Bundy, 2004; Cordier et al., 2019). Two experienced occupational therapy clinicians trained and calibrated in the POM and ToP analysed the video footage and were blinded to all aspects of the study.

The MSEL (visual motor, and expressive and receptive language skills) and CSBS (imitation and social skills) were used as the primary outcome measures in the intervention. The POM, SPT and ToP were administered as secondary outcomes measures, as hypothesised skill acquisition resulting from the TOBY app use could be developmental precursors to pragmatic language, symbolic play skills, and play. Further, these assessments were all administered in the RCT where the participants were recruited; therefore, to accurately measure maintenance of skills, the use of the same instruments were warranted.

### **2.3.1 Mullen Scales of Early Learning (MSEL)**

The MSEL comprises five sub-scales that assess a child's abilities in visual reception, gross motor functions, fine motor skills, receptive language and expressive language (Mullen, 1995). The measure is a comprehensive measure of cognitive functioning for infants and pre-school children, from birth to 68 months. For this study, the gross motor scale was not administered as it was not age appropriate. The MSEL is deemed to be valid and appropriate in assessing children with ASD (Akshoomoff, 2006). Developmental quotients (developmental age divided by chronological age, multiplied by 100) were derived for the four sub-scales given some participants in the study achieved T-Scores at or below 20, thus representing three or more standard deviations below the mean. Reliability estimates are moderate (Cronbach's alpha values range 0.75 - 0.83) with a composite median value of 0.91. Inter-rater reliability was very high, with a range of 0.91 to 0.99 (Mullen, 1995).

### **2.3.2 Communication and Symbolic Behavior Scales Developmental Profile**

#### **Caregiver Questionnaire (CSBS)**

The CSBS is a caregiver-reported standardised assessment designed to measure: 1) speech skills, such as sounds and words; 2) social-affective skills, such as emotion and eye gaze, communication, and gestures; and 3) symbolic abilities, such as understanding and object use of children (Levy et al., 2003). The caregiver questionnaire was used in this study.

The measure has moderate to strong concurrent validity ( $r = 0.59 - 0.61$  and  $0.65 - .071$ ) with reference to the one-page caregiver report checklist and behaviour sample (face-to-face) of the same assessment, indicating its validity as a tool for measuring the communication and language skills of young children (Wetherby, Allen, Cleary, Kublin, & Goldstein, 2002). The CSBS has moderate to strong test re-test reliability ( $r = 0.64 - 0.91$ ) for the checklist questionnaire and behaviour sample. The scales also exhibit high internal consistency (Cronbach's alpha range  $0.86 - 0.92$ ) (Wetherby & Prizant, 2002).

#### **2.3.3 Pragmatics Observation Measure (POM)**

The POM is a 27-item observer rated instrument of pragmatic aspects of language based on direct observation (Cordier et al., 2019). The POM has evidence for excellent inter-rater reliability ( $0.89$ ) and internal consistency (Cronbach's alpha  $> 0.98$ ). The measure has excellent criterion validity ( $0.95$ ), good construct validity ( $0.55 - 0.77$ ) and high responsiveness to change (sensitivity =  $79.7\%$ ; specificity =  $89.6\%$ ).

#### **2.3.4 Test of Playfulness (ToP)**

The ToP measures combined presence of four the elements of play: internal control, freedom from unnecessary constraints of reality, intrinsic motivation, and framing (the ability to give and read social cues) to measure the concept of playfulness. The measure is a 29-item observer-rated instrument suitable for children between 6 months and 18 years. Based on raw scores, the ToP has moderate test-retest reliability with significant intra-class correlation  $0.67$



( $p < 0.01$ ) (Bundy, 2004). Further, the ToP has evidence for excellent inter-rater reliability, supported by data from 96% of raters who fitted the expectations of the Rasch model. The measure demonstrates good construct validity with data from 93% items and 98% of people fitting Rasch expectations (Bundy, 2004).

## **2.4 Interviews with Parents**

After the assessment, participants were asked a series of open-ended questions lasting between 5 – 15 minutes to provide further explanation regarding the continued use and maintenance of skills learnt while using the TOBY app. The qualitative data was explanatory in nature with the intention of clarifying quantitative responses and not conduct in-depth interviews. All interviews were recorded on a digital voice recorder and were transcribed verbatim.

## **2.5 Intervention**

The TOBY app comprises the following three types of tasks: solo, partner, and natural environment tasks (NET). Children begin the intervention with activities at their current level of functioning and progress through the curriculum at their own rate of development and ability. Solo tasks are completed by the child independently (e.g., the child is required to find a stimulus picture among a set of three pictures presented on the screen), while partner tasks are undertaken with caregivers' assistance for recording responses or providing prompts and stimuli (e.g. the child is presented with a stimulus picture on the screen and is asked say the object's name to the caregiver, who provides prompts as necessary) (Venkatesh et al., 2013). The NET tasks are performed separately from the iPad with caregiver support and are integrated into daily life to encourage generalisation of skills learnt during solo and partner tasks (e.g., the child must say the names of clothing items as the caregiver and child sort laundry together). Responses to each task are inputted into TOBY app, and a syllabus of

future tasks is tailored for the child. This intervention can be delivered in the home by the parent or caregiver, without the direct involvement of health professionals (Moore et al., 2015; Venkatesh et al., 2013). For more information about the TOBY app, refer to the intervention description in the published RCT of the intervention ( [REDACTED] ).

## **2.6 Data Analysis**

Outcome measure data were managed and analysed using SPSS<sup>®</sup> 25 (IBM Corporation, 2015). Descriptive statistics were used to analyse the demographic data and application use of the sample. Linear mixed models were used to measure change over time at baseline (T1), post-intervention (T2) and follow-up (T3) using the fixed effect of time with an autoregressive covariance matrix to define the within-subject error, using coefficients estimated via maximum likelihood. Post-hoc pairwise comparisons were conducted from T2 to T3 to determine maintenance of the intervention. A linear mixed model was used given its suitability for modelling the influence of nonlinear individual differences across time and an approach recommended for the evaluation of psychological clinical trials (Hamer & Simpson, 2009; Krueger & Tian, 2004).

Analysis of open-ended responses was guided using the thematic analysis approach outlined by Braun and Clarke (2006). The approach is more descriptive when analysing the data, relying less on interpretation by the researchers and more on the description of experiences by participants (Creswell, 1998). Thematic analysis allows the researcher to highlight the similarities and differences across the data set, provide a large amount of flexibility and is useful when using large bodies of data (Braun & Clarke, 2006). NVivo<sup>®</sup> (version 12) was used as the data management software. All interviews were conducted by the same researcher, the fourth author, to enhance consistency. Summaries of the interviews were sent to the participants for member checking to ensure the accuracy of their responses

prior to thematic analysis. All inconsistencies were corrected prior to commencing thematic analysis. Line-by-line coding and categorisation were completed by the first author using the transcriptions of the interviews. The data were then analysed for trends and patterns of word use, frequency, their relationships and structures of discourse of communication. Throughout the data analysis, process interpretations were cross-checked across several research meetings between the first and fourth authors until consensus was reached. Finally, a clear audit trail using thematic analysis was maintained throughout the process.

### **3.0 Results**

#### **3.1 Areas showing continued improvements during observation period of three months**

Means and standard error for all baseline (T1), post-intervention (T2) and follow-up (T3) scores for all outcome measures for the 15 children participants are summarised in Table 2. Data are pooled for a group level analysis. Some participants met ceiling scores in the CSBS speech domain ( $n = 6$ ) and SPT ( $n = 3$ ). No other outcome measures were impacted by ceiling scores. The mean follow-up time post intervention was 14.5 months (range = 12 to 18,  $SD = 1.85$ ). Pre-post intervention analysis using the three time points of the participants demonstrated statistically significant improvements in the: 1) MSEL receptive language subscale; 2) social, symbolic and speech subscales and the total composite score of the CSBS; 3) POM; and, 4) ToP (see Table 2). Post hoc analysis using pairwise comparisons demonstrated statistically significant improvements between T1 and T2 for MSEL receptive language subscale ( $p = .014$ ), CSBS social communication subscale ( $p = .003$ ), CSBS symbolic subscale ( $p = .001$ ), CSBS speech subscale ( $p < .001$ ), CSBS total composite score ( $p < .001$ ), POM ( $p = .002$ ), and ToP ( $p = .007$ ). Importantly, no significant differences were detected between T2 and T3 time points for the outcomes MSEL receptive language subscale ( $p = .054$ ), CSBS social communication subscale ( $p = .160$ ), POM ( $p = .809$ ), and ToP ( $p =$

.172); indicating that the participants' skills did not improve after ceasing the intervention, however, they also did not regress in these skill areas, suggesting maintenance.

Statistically significant improvements were detected between T2 and T3 time points for the CSBS symbolic subscale ( $p = .005$ ), CSBS speech subscale ( $p = .044$ ), and CSBS total composite score ( $p = .002$ ). However, these improvements could be attributed to natural development and should be interpreted with caution. Furthermore, with a considerable number of participants achieving ceiling scores on the CSBS speech (40%) outcome measure, there is limited evidence supporting the continued improvement in this skill area from T2 to T3. However, the absence of a statistically significant difference between these time points still supports the maintenance of skills in these areas. No statistically significant decline in scores was detected from T2 to T3 for any outcome measure. These findings demonstrate the receptive language, social skills, pragmatic language and playfulness of children with ASD improved during the three-month intervention period and were maintained at least 12 months after ceasing the TOBY app intervention for participants in this study.

### **3.2 Comparison between RCT and follow-up study results**

While improvements in expressive language were detected between the intervention and control groups in the RCT, the comparison of the intervention and control groups in this follow-up study could not be completed due to the waitlist design of the RCT. That is, all participants regardless of their allocation to the intervention or control group for the RCT received the TOBY app intervention. Notably, the final time point in the study by [REDACTED] was completed at three months (T3) compared to the longer follow-up time point at 12 months (T4) in this study. See Figure 2 for the comparison of maintenance of skill acquisition at the longer follow-up period (at least 12 months) in this study to the findings from the RCT study that had a shorter follow-up period (three months).

**Table 2.** Linear Mixed Model - Means and Standard Error for all Baseline, Outcome and Follow-up measures pooled.

		Baseline (T1)	3-Month (T2)	Follow-up (T3)	<i>F</i> -score	<i>p</i> -value
MSEL	Visual Reception	72.6 (6.01)	79.8 (6.1)	70.9 (6.01)	2.347	.118
	Fine Motor	66.0 (5.24)	71.1 (5.24)	65.6 (5.24)	2.446	.111
	Receptive Language	62.5 (6.34)	72.7 (6.45)	70.3 (6.93)	3.725	.042*
	Expressive Language	62.7 (6.39)	66.1 (6.55)	67.3 (6.39)	.771	.476
SPT	Age Equivalent <sup>§</sup>	31.9 (1.40)	31.4 (1.39)	31.1 (1.38)	.279	.759
CSBS	Social Domain	31.1 (1.76)	34.8 (1.72)	36.4 (1.74)	10.730	.001*
	Speech Domain <sup>§</sup>	31.7 (1.36)	36.8 (1.29)	39.3 (1.32)	14.072	< .001*
	Symbolic Domain	38.5 (1.30)	42.9 (1.22)	46.5 (1.25)	13.659	< .001*
	Total Composite	101.23 (3.50)	114.6 (3.33)	122.1 (3.34)	26.678	< .001*
POM		11.6 (8.60)	38.8 (8.60)	36.8 (8.60)	5.774	.008*
TOP		47.24 (3.97)	59.49 (3.97)	53.6 (3.97)	4.316	.026*

\*Significant difference (*p*-value > .05)

<sup>§</sup>Ceiling Effect

MSEL: Mullen Scales of Early Learning

SPT: Symbolic Play Test

CSBS: Communication and Symbolic Behaviour Scale

POM: Pragmatic Observation Measure

TOP: Test of Playfulness

		RCT study (n = 59)			Follow-up study (n = 15)	
		Between-group comparison (T1 – T2) <sup>a</sup>	Pre-post intervention (T1- T2) <sup>b</sup>	Maintained skills (T2 – T3)	Pre-post intervention (T1 – T2)	Maintained skills (T2 – T4)
MSEL	Visual Reception§					
	Fine Motor					
	Receptive Language		•	•	•	•
	Expressive Language	•				•
SPT	Age Equivalent§					
CSBS	Social Domain		•	•	•	•
	Speech Domain <sup>§</sup>				•	†
	Symbolic Domain		•	•	•	†
	Total Composite <sup>§</sup>	×	×		•	†
POM			•	•	•	•
TOP					•	•

<sup>a</sup> Intervention vs Control

<sup>b</sup> Pooled participant data

<sup>§</sup> Ceiling Effect

• Statistically significant difference

† Improved significantly from T2 to T4

× Not reported in RCT study

MSEL: Mullen Scales of Early Learning

SPT: Symbolic Play Test

CSBS: Communication and Symbolic Behaviour Scale

POM: Pragmatic Observation Measure

TOP: Test of Playfulness

**Figure 2.** Comparison of maintenance of skills at three months (T3) and at greater than 12 months (T4).

### 3.3 Parent responses

In addition to using standardised outcome instruments to measure the developmental outcomes of the children who participated in study 12 months after the intervention, the study sought to seek parents' opinions on the continued use of the app and the maintenance of skills learnt while using the TOBY app. Thirteen out of 15 parents reported no longer using the app or using the app 'very little' after the initial three-month intervention period. Parents reported a number of reasons as to why they had stopped using the application since the trial ceased, with the main findings summarised in Table 3. A lack of time and a loss of interest from their child in the application were cited as the main reasons. Other key findings from the interviews were the TOBY app's level of difficulty became too easy for their child, which contributed to a loss of interest for both the parents and children and discontinued use was due to parents changing the therapy goals for their child towards skills that the TOBY app did not target. Finally, 12 out of 15 parents reported their child had maintained at least one skill they developed while using the TOBY app, including receptive language, social communication or daily living skills — thus supporting the quantitative findings of maintenance in these skill areas. Triangulation by analysing the individual changes for each child from T2 to T3 for each outcome measure confirmed these parent reports.

**Table 3.** Thematic representations of parent interviews on continued use of the TOBY app and their child's maintenance of skills.

Topic	Themes	Common responses
Discontinued use of the TOBY app	Lack of time	<ul style="list-style-type: none"> <li>• Difficult to fit in the 20 minutes a day</li> <li>• Caring responsibilities to other children</li> <li>• Child beginning school</li> <li>• Lifestyle factors of returning to work or having another child.</li> <li>• Extra-curricular activities</li> <li>• Tedious to read the instructions and takes too much time.</li> </ul>
	Skills taught by the TOBY app were no longer the goal	<ul style="list-style-type: none"> <li>• Wanted to work on social behaviour which mother thinks are not covered by TOBY</li> <li>• Needed to focus on other forms of therapy to build social skills and sensory related issues.</li> <li>• Needed that time and effort to focus on other therapies.</li> </ul>
	Child lost interest	<ul style="list-style-type: none"> <li>• Could not focus on the TOBY app for 20 minutes a day.</li> <li>• As the tasks were too easy, the child got bored.</li> <li>• Not enjoying application</li> <li>• The child got frustrated at the voice on the TOBY app</li> <li>• Novelty wore off</li> <li>• Was not a game, and did not have music, so the child was not motivated</li> <li>• Child perseverated on the rewards and not the activities</li> <li>• Difficulty staying engaged after the favourite activities were completed.</li> <li>• Got bored towards the end of the trial</li> <li>• Child got frustrated because they wanted other apps on the iPad, and as there were no others, would not use the iPad.</li> </ul>



Topic	Themes	Common responses
	Better for the earlier stages of development	<ul style="list-style-type: none"> <li>• Enjoyed using it when child was younger</li> <li>• Too easy and not benefiting the child</li> <li>• Parent does not see point in using it, as it will be no benefit due to tasks being too easy now.</li> </ul>
	Challenge finding the “just right” level for child	<ul style="list-style-type: none"> <li>• Could not skip levels so did not have time to get to the activities that would be beneficial for the child.</li> </ul>
Skill Maintenance	Maintained skills	<ul style="list-style-type: none"> <li>• 12 out of 15 parents reported maintenance in at least one skill area in language, daily living skills and social communication, such as listening to and following instructions</li> </ul>

## 4.0 Discussion

Outcomes of this study follow on from the findings by [REDACTED] who reported limited effectiveness of the TOBY app in improving the receptive language, social and symbolic communication, pragmatic language when analysing pre-, post- and follow-up data of children with ASD. When the findings from the study by [REDACTED] and this longer-term follow-up study are combined, it can be concluded that participants who use the TOBY app for three months gained and maintained skills for up to at least 12 months for receptive language, social and symbolic communication, pragmatic language and playfulness. However, due to the absence of a control group to account for confounding variables, such as natural development, and a small sample size at the 12-month follow-up, caution should be exercised when interpreting the findings. No skill improvements were detected in the SPT and the MSEL visual reception, fine motor and expressive language subscales between pre- and post-intervention.

This study is one of a few to investigate the long-term outcomes of a parent-mediated ICT-based psychosocial intervention for children with ASD. These findings extend the current knowledge about parent-mediated ICT-delivered interventions for children with ASD, indicating the limited effectiveness of the TOBY app for children with ASD who live in regional areas. Together with findings from Pickles et al. (2016) and Estes et al. (2015), results from this study contribute to the emerging evidence to support the long-term benefits and maintenance of skills where parents are active agents in the delivery of therapy for children with ASD who live in regional areas.

Use of the TOBY app was anticipated to lead to improvements in the longer term for the skills of language, social communication and playfulness as the children developed, given the TOBY app's focus on fundamental skill development in these areas. That is, the TOBY app curriculum includes tasks targeting skills in early child development, which can be built

on and generalised to more complex skills as the child develops (Moore et al., 2015; Venkatesh et al., 2013). Interestingly, the only statistically significant changes measured after the cessation of the intervention were in social communication, as measured by the CSBS. A possible explanation for this finding could be a ceiling effect of the MSEL, CSBS and SPT measures, resulting in a decreased sensitivity to detect change as children approach the upper end of possible scoring. However, the POM and ToP outcome measures have demonstrated psychometric validity and reliability for older children, so have higher responsiveness to detect development in these skills for participants in this study. Despite no statistically significant improvements the MSEL, POM and ToP outcomes from T2 to T3, the overall findings across all measures did not detect a decline in any skills over the follow-up period, supporting the maintenance of these skills.

In the RCT from which the participants were recruited, pre-post intervention analysis of the pooled participant data ( $n = 57$ ) showed changes in the sub-scale of receptive language in the MSEL, social and symbolic subdomains of the CSBS, and the POM but not playfulness [REDACTED]. Interestingly, in this study when follow-up was extended to 12 months or greater, the playfulness of the children had improved over the intervention period (T1 to T2). However, there was no statistically significant improvement from T2 to T3 in the ToP, suggesting no developmental gains in playfulness over this time period.

While playfulness was not a targeted skill area within the TOBY app curriculum and was not a primary outcome in this study, skills such as receptive and expressive language, joint attention, and gestures learnt from the TOBY app could be vital precursors in the development of children's play skill (Kaale, Smith, Nordahl-Hansen, Fagerland, & Kasari, 2018; Kasari, Gulsrud, Freeman, Paparella, & Hellemann, 2012; Moore et al., 2015). Playfulness, as a construct measured by the ToP, is determined by evaluating the presence of internal control, intrinsic motivation, the freedom to suspend reality, and skills related to

framing (Bundy, 2004; Cordier, Bundy, Hocking, & Einfeld, 2009). Relevant to the skills the TOBY app targets, framing in the construct of playfulness requires skills in the ability to read and give social cues (Bundy, 2004). It was anticipated that the language and social communication skills learnt during the trial period could have resulted in improvements in the playfulness of the child; however, these were not detected at 12 months follow-up. This could indicate that generalisation of social communication skills taught in the TOBY app to spontaneous play interactions are limited, reinforcing similar findings in play-based interventions and highlighting the need for targeted interventions for children with ASD to improve skills in play (Henning, Cordier, Wilkes-Gillan, & Falkmer, 2016; Ingersoll & Schreibman, 2006; Williams White, Koenig, & Scahill, 2007).

Twelve out of 15 parents reported their child had maintained at least one skill at 12 months post-intervention in one of the areas of receptive language, social communication or daily living skills, despite them no longer using the TOBY app. Triangulation by analysing the individual changes for each child confirmed these parent reports, thus, supporting the findings of skill maintenance in this study. Despite 12 parents reporting a maintenance effect in at least one skill the TOBY app was targeting, three parents reported no maintenance effect. This finding indicates that the TOBY app may not be appropriate for all children with ASD in the long-term. This finding is congruent with another study where in-depth interviews were conducted with parents exploring the overall experience of the TOBY app; however, further research into the parent and child factors that influence the maintenance of skills is warranted [REDACTED].

Further, responses from the parents indicated 13 out of the 15 children were no longer using the TOBY app after twelve months, citing a lack of time and a loss of interest from their child as common reasons. The cessation of the TOBY app after three-months was mirrored in the study by Whitehouse et al. (2017), who reported a significant decline in per

day median use from approximately 19 minutes during the first three months, to a per day median use of two minutes over the following three months. Parents from the Whitehouse et al. (2017) reported the main reasons for discontinued use were similar to those reported in this study, a lack of time and loss of interest in the TOBY app by their child. The discontinued use of the TOBY app could be viewed from a positive perspective. Parents reported the activities on the TOBY became too easy for their child and did not match their child's changing preferences since the initial intervention period. Hence, participants may have ceased using the TOBY app due to the child having developed the skills the TOBY app was addressing and maintained those skills; therefore, parents no longer felt the need to use the TOBY app anymore.

The development and evaluation of ICT-based interventions for more complex skills in older children with ASD are warranted. The key reasons as reported by the parents for the cessation of the intervention was their child losing interest in using the app and the tasks became too easy for their child. When developing the curriculum, developers and researchers should consider the scope of the curriculum and could include tasks and activities that target higher-level skills and are appropriate for children who are developmentally more advanced.

Findings from this study can also inform service providers who support families of children with ASD living in regional areas. While the TOBY app provides an engaging experience for parents and their children in the short-term, it was clear that the activities provided by the application were not graded to sufficient levels of complexity and were not challenging enough to keep the child with ASD engaged in the long-term. Despite the geographical barrier, regular contact should be maintained with the family to ensure the broader intervention plan evolves through alternative activities or to include content with increased complexity to meet the child's evolving learning needs. Videoconferencing is a feasible modality that may be beneficial for parents to communicate directly with service

providers, particularly for those who live a considerable distance away (Wainer & Ingersoll, 2015). Larger scale studies, using control groups with an a priori long-term data collection point in the study design could improve the generalisation of results to broader populations, which was a limitation of this study. Lastly, researchers should focus on the most effective components of ICT-based interventions to improve the generalisability of skills learnt through ICT-based intervention, a common limitation of cited in the literature of ICT-based interventions for children with ASD (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014; Silver & Oakes, 2001).

A number of limitations are present in this study. Consideration of the findings in the context of the study design is required. The study followed-up with a small non-randomised sample, limiting the ability to control for confounding factors. Further, given the lack of a control group, which was unavoidable due to ethical considerations, the development of skills in the children with ASD could be attributed to typical development in the children. However, the lack of statistically significant improvements from T2 to T3 in the MSEL, POM and ToP suggest this may not necessarily be the case. The recorded app use that determined group allocation was only available for the total duration of app use, i.e, baseline to follow-up (T1 to T3), thus app use during the follow-up period (T2 to T3) was unable to be derived from the dataset. As this was a long-term follow-up, the age of the participants resulted in a ceiling effect in some of the outcome measures as the instruments were chosen to assess younger, less developed participants in the RCT effectiveness trial. A number of participants achieved ceiling scores in the CSBS speech (40%) and SPT (33%) outcome measures, thus, decreasing the sensitivity of these measures to detect change; however, given no statistical difference was detected, measuring the maintenance of skills is still valid for these outcome measures.

## **5.0 Conclusion**

This study investigated the long-term follow of an ICT-based intervention, the TOBY app, for children with ASD living in regional Australia to determine the maintenance or continued improvement their language and social communication skills after at least 12 months post-intervention. Findings demonstrate the receptive language, social skills, pragmatic language and playfulness of children with ASD improved during the three-month intervention period and were maintained at least 12 months after ceasing the TOBY app intervention.

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