

Thinking in Pictures Educational Services (TIPES): A Preliminary Report of an Intensive Behavioral Intervention for Children with Moderate to Severe Autism Spectrum Disorder

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ABSTRACT

Introduction: Autism spectrum disorder (ASD) is a potentially severely disabling exceptionality, and there is evidence of increasing incidence. In extreme cases major challenges can develop early in childhood for those individuals, their families and educational services. Social isolation, language problems, sensory and behavioural problems can all become entrenched if effective support is not provided. Interventions capable of delivering a recovery trajectory with transition to public/private education for children with moderate to severe ASD have been infrequently reported in the literature. Intensive behavioural intervention (IBI) as delivered within the Thinking in Pictures Educational Services (TIPES) has, as yet, not been tested as an intervention for children with moderate to severe autism.

Methodology: IBI was delivered over a minimum of 12 months with 25-40 hours of individual therapy per week. Following a baseline memory paradigm assessment, a participant-specific IBI intervention was delivered. A combination of discrete trial training and ESDM, verbal behavior approach followed by direct instruction programs were used to improve language and social functioning. Baseline and end of intervention Assessment of Basic Language and Learning Skills-Revised (ABLLS-R) scores were recorded and compared to standard age adjusted mean childhood scores for educational ability. Each participant was assessed Assessment of Autism Treatment Evaluation Checklist (ATEC) in order to evaluate the impact of the intervention on the 4 domains of ASD (speech, sociability, sensory, behaviour performance). The primary end point was taken as the last score on the ATEC and ABLLS-R. The primary outcome was attendance in public and privately funded classroom settings.

Results: All results within this study were significant. In terms of the primary outcome 9 out of 14 children with moderate to severe childhood ASD treated with IBI, using the TIPES method attended public/private funded sector education during the second year. There was an effect size (number needed to treat) of 2 indicating a very effective intervention. Basic language and learning skills as scored on the ABLLS-R significantly improved (p<0.000). Core characteristics of ASD as measured on the ATEC total scores significantly improved at end of treatment (p<0.012). All ATEC subscale scores significantly improved. Baseline mean speech scores significantly improved (p<0.006) as did sociability (p<0.005), sensory (p<0.078) and behaviour scores (p<0.041).

Conclusion: This preliminary study indicated that educational attendance was possible for the majority of children with moderate to severe ASD who were accepted by TIPES and treated with an individualised combined IBI approach based on memory and learning capacity. If these results can be replicated this would be a highly cost-effective intervention.

Keywords: ASD; IBI; TIPES

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INTRODUCTION

Autism spectrum disorder (ASD) develops prenatally with accelerated growth of the foetal brain. The areas showing most rapid growth include the corpus callosum with a 67% increase in cell numbers and the amygdala [1]. This brain growth is maintained by 24 years of age but by adolescence the brain is smaller in size than peers without autism [2]. Interestingly, the corpus callosum mediates inter-hemispheric connectivity and the amygdala is the main memory and emotional processing centre in the brain. These changes are thought to lie at the root of theory of mind problems which manifest as impaired empathy. The causes are unknown but there is a definite genetic contribution to causation [3]. The only other proven causes are maternal infection with cytomegalovirus or rubella [4]. It is thought that the current incidence of ASD is 1 in 69 in the United States. Identifying and correctly diagnosing individuals with ASD can be difficult as the characteristics usually develop slowly over time and vary from person to person. ASD ranges in severity from manifesting along with pervasive developmental disorder (with moderate to severe learning disability) to Asperger's syndrome (high functioning autism where intelligence is normal or high). In DSM-V, a score of level 1,2 or 3 is allocated by considering the two domains (impairment in social communication and restrictive repetitive behaviours) [5]. Those with level 2 or 3 ASD have moderate to severe characteristics and require more substantial support. On a less stigmatizing note, the brains of those with ASD have been described as being, 'uniquely synchronized' and neuroimaging research has found discrete and clear patterns of enhanced connectivity [6]. Resting neuroimaging also showed functional differences. It was noted that the findings from this study could not clarify if these brain functioning differences (increased activity in amygdala and prefrontal cortex) were a manifestation of ASD or were actually the cause of ASD [7,8]. A cardinal characteristic of ASD is impaired empathy. This makes it difficult to develop and sustain relationships and can lead to emotional instability, anxiety and depression. The second cardinal feature of ASD is repetitive and ritualistic behaviour which can be perceived as being inappropriate in social situations. When problems with empathy and repetitive behaviours are prominent learning environments can be perceived as challenging which leads to failure to achieve their academic potential. As such, children with moderate to severe ASD usually find sustained attendance at public or private education to be very difficult or even impossible.

There have been previous attempts to investigate different intervention strategies with the aim of ameliorating the characteristics of autism and improving educational trajectory and entry into classrooms both in the private and public setting [9]. One such study reported considerable improvements in some areas of functioning for children with ASD across a sevenmonth follow up period [10]. In this cohort study of children with ASD language development, social interaction and positive behaviour all improved. Also, on an educationally focused intervention children with ASD demonstrated improved intelligence over time as measured by IQ [11]. However, in these small studies the findings are difficult to interpret due to lack of power and the wide spectrum of severity included. It was however demonstrated that parental/guardian support seemed to be a key element in delivering a successful outcome. It was concluded that the best predictor of improved outcome in terms of a durable benefit for children with moderate to severe ASD was the amount and quality of family care and support that they received. There also seemed to be evidence of responders and non-responders to these interventions. Some children with ASD were found to dramatically improve and others found to make little or no improvement. It may be that the children who were less responsive with ASD needed a more prolonged intervention than was given. A long-term study of 96 adults with moderate to severe ASD found that almost all remained fully reliant on their parents at follow up. A key predictor of a good outcome was that those with better communication skills achieved a better quality of life and functioned relatively well despite not achieving independence. It was reported that 1 in 8 of the study group were employed full time. There were examples of outstanding success. At long-term follow up one man with ASD was married with a child and was working as a highly successful music director [12]. However, there were two other long term follow up studies with poorer outcomes [13,14]. These two studies followed up the progress of 29 adults with ASD. They reported that only one of the adults with ASD achieved full-time employment. An alarming 63% of the study group had been rated as having a severely poor social outcome, and only 23% were rated as having a positive social recovery. In support of these findings another long term follow up study reported very similar results [15]. Only one person from this study group was positively functioning and living independently. Around half of the remaining group was rated as having a poor quality of life. These findings certainly suggest that effective intervention options are required for children with autism to prevent such negative outcomes. It may be possible with an effective childhood intervention to improve the subsequent trajectory. Improvement in children with ASD, both in their communication skills and behaviour can greatly impact their ability to engage in public and private education leading to a positive quality of life in the medium term.

What the present study may add to the literature: This preliminary study attempted to discover whether a cohort of children with moderate to severe core characteristics, as measured on the four ATEC categories, could improve enough to attend a classroom in the private or public educational system. It further evaluated whether the children could learn and acquire more skills based on the ABLLS-R curriculum.

METHODOLOGY

Description of participants and how IBI was used in this cohort

Thinking in Pictures Educational Services (TIPES) is a charity offering individualized intensive combined behavioural for children with ASD and/or related treatments exceptionalities. The memory paradigm as described in the low performers, manual, records the number of times a child needs to practice a task before they retain the information and are able to perform the task independently [16]. At TIPES the result determines the Applied Behavioural Analysis (ABA) model chosen to implement with the child. For example, a child who needs to repeat a skill 100 times typically requires discrete trial training to retain information. Once the individual learns to retain information with less repetition then they can start using other models of ABA such as Early Start Denver Model (ESDM) or Verbal behavior approach.

The current study is based on a sample of clients who were registered at TIPES in September 2018 through June 2019. Eighteen clients were offered the chance to participate in the study however, only fourteen agreed. Six of the children in the study had participated in other ABA programs but had not demonstrated significant improvements. All six children either participated in solely an Early Start Denver Model (ESDM) or verbal behaviour program or had never participated in a discrete trial training program. The memory paradigm indicated that neither the ESDM or Verbal behaviour model were appropriate for the individuals at the time. All were provided with the discrete trial training model until the number of repetitions they needed to retain the information was reduced. Within the cohort all of the children were diagnosed with ASD and had a minimum of one year of treatment and the ABLLS-R and ATEC were used to assess baseline data and to track developmental changes. All participants were registered for 25-40 hours of IBI therapy per week. During the second year, the majority of children were starting to transition out of therapy and into part time classroom settings. At the commencement of treatment each child was enrolled in one on one IBI therapy. Therapists were trained in applied behaviour analysis and supervised by the supervising clinician. Depending on the child's development the use of ESDM, Discrete trial training and verbal behaviour were used to deliver the IBI programs. Direct instruction programs were then used to apply many of the ABLLS-R programs in a conversational and reciprocal format. In terms of the gender and age of entry into TIPES for the study cohort there were 11 males and 3 females and the mean age of entry was 62 months (Range 29 months to 104 months).

ABLLS-R

The Assessment of Basic Language and Learning Skills-Revised (ABLLS-R) is a baseline assessment and curriculum used to determine skills of children with ASD and developmental disabilities [17]. The ABLLS-R provides 25 development areas and breaks them down into skills typically acquired before grade one. These skills include but are not limited to; cooperation, visual performance, receptive and expressive language skills as

well as toileting, social, fine and gross motor skills and beginning academic skills.

ATEC

The Autism Treatment Evaluation Checklist (ATEC) is designed to determine the severity of the child's ASD characteristics on a scale from 1 to 169, 169 being the most severe [18]. The characteristics are broken down into 4 categories: Speech, Sociability, Sensory/Awareness and Health/Physical/Behaviour. This is a valid measure to evaluate the child's progress and to determine the effectiveness of the IBI program implemented. If the child is improving the scores would reduce every six months. This would also indicate that programs were applied appropriately and targets were accurately chosen.

Description of scales used and timings

Six month intervals were used to re-assess and compare the child's developmental progress following the baseline assessment using both the ABLLS-R and the ATEC. Reports were then analyzed to ensure that the child was continually learning, that the educational programs were effective, and that future targets were being identified.

Description

Parents signed a consent form to begin treatment prior to implementing baseline assessments. A supervising therapist completed an ABLLS-R assessment and then worked with the parents to complete an ATEC questionnaire. Once the ABLLS-R and ATEC assessments were completed and the results were recorded by the clinical team future goals for the child's programs were determined. Frequency graphs showing the number of skills acquired per program were updated daily. The parents and clinical team met on a monthly basis to continually evaluate and update programs. These meetings also allowed the parents or guardian to be involved with the child's programming and be fully updated with the child's progress. Senior therapists supervised the IBI therapy at 10% of the hours completed per week for the remainder of each month. Once the child completed 6 months of therapy, the parents and clinical team reassessed using the ABLLS-R and ATEC, reviewed all programming and determined what new skills should be taught, generalized or maintained.

STATISTICAL ANALYSIS

In terms of the primary outcome, number needed to treat (NNT) was used. This is defined as the number of clients who need to be treated with a new treatment rather than the standard treatment for one additional client to benefit. A low NNT indicates a highly effective treatment. In terms of the other secondary outcomes paired t-tests were used and reported with standard deviations and p values.

RESULTS

In terms of the primary outcome, 9 out of 14 children attended a public/private school after completion of IBI therapy at TIPES. This is an NNT of 2. Of the nine students four attended full-time school without the assistance of an educational assistant (2 of the children went to private schools and 2 went to public school). One student attended a private school with access to an Educational assistant when needed. Four students were in transition from IBI to part time school in a low ratio ABA based classroom to teach them how to learn in a group setting, while the remaining 5 students continued IBI.

1. A paired samples t-test found there was a significant difference between ABLLS-R baseline scores compared to their end scores, (M=214.285; SD=219.702) t(3.805); p=0.002).

2. A paired samples t-test found there was a significant difference between ATEC total baseline scores compared to their end scores, (M=38.571; SD=24.656) t(5.853); p=0.002.

3. A paired samples t-test found there was a significant difference between children's ATEC baseline scores for Speech compared to their end scores, (M=9.000; SD=4.242) t(7.937); p=0.000.

4. A paired samples t-test found there was a significant difference between children's ATEC baseline scores for Sociability compared to their end scores, (M=10.000; SD=7.179) t(5.212); p=0.000.

5. A paired samples t-test found there was a significant difference between children's ATEC baseline scores for Sensory compared to their end scores, (M=10.071; SD=8.334) t(4.522); p=0001.

6. A paired samples t-test found there was a significant difference between children's ATEC baseline scores for Behaviour compared to their end scores, (M=9.142; SD=9.045) t(3.782); p=0002.

7. The effect size of this study was 1.8 (NNT of 2).

DISCUSSION

All results within this study were significant. Nine out of fourteen of the children with moderate to severe autism returned to classroom education with the help of the TIPES IBI intervention. The intervention included the educational materials and schoolroom reading and comprehension products of the Science Research Associates publishing company in Chicago. Approximately 80% of all children significantly improved on the ATEC total score over time. All group results were significant on the ABLLS-R and ATEC scores for Speech, Sociability, Sensory and behaviour. A finding of within 300 points of the normal childhood trajectory at baseline showed a tendency to predict return to classroom education. This indicated that the children who were at a higher level of baseline functioning were more likely to respond and that a longer intervention might have been needed for the others. There is a non-statistically significant signal that TIPES IBI optimally improves children's speech and sociability within ASD. No children within this study group deteriorated but three out of fourteen did not make significant improvements within the time period. Within this group there was one child whose sensory needs increased due to a coexisting neurological disorder which improved following treatment with medication. This paper supports the use of various ABA models and indicates that they can all work if prescribed at the right time in relation to the child's memory needs.

There are numerous different applications of IBI for autism but there is little in the way of published research which replicates early ground-breaking findings [19,20]. The two main categories of intervention available for individuals with ASD are based on behavioural and communication theories. Discrete Trial training, ESDM and Verbal Behaviour are all forms of applied behaviour analysis (ABA) that are taught one on one in intensive behavioural intervention (IBI). Discrete trail training involves teaching children with ASD skills in a repetitive manner in discrimination until mastery. This method can be used for individuals with ASD at all ages. However, for very young children with ASD, the developmentally appropriate play based model ESDM is often recommended. Verbal behaviour models are typically used for students who are ready for a more natural type of teaching with less table time and fewer repetitions. Intensive behavioural intervention (IBI) as tested in this cohort aimed to improve outcomes by increasing positive behaviours and at the same time reducing negative ones. Pivotal response training (PRT) has an emerging evidence base and focuses on developing self-motivational ability leading to improvement in communication and socialising skills. In addition to the above researched methods there is Treatment and Education of Autistic and Related Communication-handicapped Children (TEACCH). This treatment works by aiding the child with autism with visual prompts such as picture cards to help the child learn everyday skills like brushing their teeth or making their bed to develop skills through small and understandable learning steps. Another variant is to teach children with ASD to communicate and learn through symbols rather than images. Randomised controlled trials are not available to allow comparison of efficacy and there are a lack of publications to describe and compare combined interventions.

IBI can be increased in terms of its effectiveness by adding Occupational Therapy which attempts to develop self-help skills and gross and fine motor skills. Like many of the other interventions the goals include helping the child learn everyday social and self-help skills such as eating, drinking, dressing and cleaning and how to socialise and communicate with others around them. Sensory Integration Therapy (SIT) is focused on sensory problems that the child with autism is having (any sensory issues that aggravate the child). If for example, the child struggles with sensory input from bright lights or certain sounds, this intervention will teach the child to cope and move forward whilst dealing with these problems.

As far as medications go for treating autism there are no evidence-based options except for the treatment of co-morbid conditions such as ADHD. Autism is a disorder where there is no direct medical treatment for the core characteristics. However, there are some medications available that can alleviate the behavioural manifestations of the disorder and in turn help the individual cope better. Risperidone is an antipsychotic, tranquilising medication and is the only drug sanctioned by the FDA for children with autism. It can be prescribed for children between 5 and 16 years old to help with agitation. Antidepressants such as Selective serotonin reuptake inhibitors (SSRIs), anti-anxiety medications and stimulants however, are not sanctioned except to treat comorbidities. In terms of diet and nutrition there is no evidence of benefit with specific nutritional plans for children with autism. A healthy balanced diet is all that can be recommended. There is some early evidence to show that removing gluten or casein from the diet might be a helpful treatment for ASD but limiting foods like dairy can prevent proper bone development and such diets are a major imposition. Gluten and lactose free diets remain experimental at the current time. It would appear that a balance of medication (if indicated) for agitation or for comorbidities, a healthy balanced diet and a combination of correctly implemented applied behavioural analysis and other interventions would be the most effective form of treatment for children with autism.

IMPLICATIONS

The implications from this study are important. IBI as delivered by TIPES has demonstrated the most powerful effect size reported in the scientific literature in the treatment of childhood autism. A grant should be submitted for IBI to be tested in a larger cohort of children with moderate to severe autism and then in a randomized controlled trial. TIPES clients may benefit from the application of CBT if anxiety, phobia or other emotional disorders supervene when the child returns to classroom education and face the challenges of adolescence. TIPES/IBI should be piloted in the treatment of other disorders linked to autism such as Angleman syndrome, Fragile X syndrome and Rett syndrome. The next step might be to pilot IBI for receptive language disorders.

There are various limitations in interpreting the current preliminary study:

1) Some children may have been attending TIPES longer than others when the IBI was begun. Some of the children who transitioned to a typical school had already been at TIPES for approximately 2.5 years.

2) Some children may have learned faster as they were younger when treatment began. Consequently, children who started IBI later may have showed slower development as they had more skills to acquire to catch up to their typical peers.

3) During the study one child was undergoing evaluation for a dual diagnosis. Months later after the completion of the study the child was diagnosed. This was a child who did not transition to public/private education.

6) The ATEC assessment was introduced in 2016. As a result, some of the students initial baseline assessments, prior to the study, did not include ATEC's. This is a limitation on the generalizability of these findings.

7) Some students had psycho-educational assessments identifying their developmental skills. However, not all the children had them so the results could not be include in the study. This is a limitation on the generalizability of these findings.

RECOMMENDATIONS

1)Future studies should include a psycho-educational assessment pre and post therapy every 2 years.

2) A long-term study should be completed to determine if the children that transitioned to a classroom setting or school remained in the classroom or school for the remainder of their educational careers.

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