What Do the Parents Say? Parents of Children with Developmental Disabilities Using Touch-Screen Mobile Devices

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Key words: children with disabilities; touch-screen mobile devices; quality of family life; satisfaction of parents of children with disability; supportive services for parents

Abstract

Purpose: This study was designed to investigate the experience of parents of children with and without developmental disabilities who use Touch-Screen Mobile Devices (TSMD) and their subjective evaluation of its impact on their children. **Procedure:** A survey was administered via the internet and via personal connections. **Results:** Statistically significant differences were found between the parents of children with a disability and those without. In general the study findings show a fairly high degree of satisfaction with the

TSMD experience among parents of children with disabilities and somewhat less satisfaction among parents of typically developing children. Reports of satisfaction among parents of children with disabilities were highly correlated with improvement in the child's positive social interaction, having clear goals for the child's use of the technology and the degree to which the parent was involved in the child's experience. Parents expressed low satisfaction with the preparation, support and instruction that they received to use the TSMD. **Conclusions:** TSMD technologies offer a non-stigmatizing tool that can complement existing support strategies to aid a child's with disabilities and the family to improve communication, social interaction, anxiety management, and relaxation. There is a need to develop supportive and guiding services for parents to help them develop meaningful goals and to encourage their participation in the child's experience.

Introduction

Children with developmental disabilities (CWDD) face many challenges in the process of achieving their potential, including difficulties in social interaction, communication, flexibility of thought and anxiety management (Lecavalier, 2006). These difficulties are often disruptive to the family and to its ability to achieve a high quality of life. In many cases children with a disability have an inability to sustain attention on tasks, thus posing difficulties for parents. The child's engagement in maladaptive behaviors, including, self-stimulatory behaviors, tantrum behavior, aggression and property destruction, frequently result in withdrawal from social interaction and increase parental anxiety (Nefdt, 2007). Often when left alone the child does not engage in functional tasks, thereby impeding the process of abstracting information from the

environment (Frith, 1989; Frith & Happé, 1994). Typically developing children (TDC) gather and retain information from their surrounding environment. CWDD often lack the ability to readily master information, leading to an increase in the developmental gap between them and their typically developing peers (Williams, 2003).

Researchers have recently begun to evaluate the ways in which TSMD devices (such as: iPods, iPhones, tablets, iPads, etc.) can offer a nonstigmatizing tool that can be used to complement existing assistive technology devices and strategies to aid CWDD and their families in the areas of communication, social interaction, anxiety reduction and relaxation (e.g., Tunney & Ryan, 2012).

This study surveys the experience of parents of children with and without developmental disabilities who use Touch-Screen Mobile Devices (TSMD) and their subjective evaluation of its impact on their child's growth and development, and the quality of family life

TSMD and **Disability**

The first iPad was released on April 3. 2010 (Apple, 2010) and 300,000 iPads were sold on their first day of availability (Harvey, 2010). The manufacturer claims to have sold 170 million iPads since the device's launch. Computer search engines identify dozens of sites advancing the use of TSMD in the home and in the classroom. Many claim that the device helps children learn better and faster (Department of Education and Early Childhood Development. 2011). In addition, dozens of web sites relate to the use of this technology specifically for persons with disability. One site indicates that students can now translate written words to verbal ones so that those with dyslexia or other reading disorders can complete work using only their voice; and those with autism can find alternative ways to express their thoughts and feelings (Ronayne, 2013).

The explosion of new mobile technologies such as the iPad and other TSMD "tablets" is just beginning to be evaluated in the professional literature. Anecdotal reports suggest that CWDD who lack speech may be able to communicate through the use of tablet-based communication devices. Experience has shown that a TSMD can be adapted and

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programmed relatively quickly and such devices would appear to represent a viable technological resource for students with disability. Students with intellectual and other disabilities were found to be able to operate a tablet independently and to access age-appropriate content (Kagohara, 2011).

There is growing interest among therapists regarding the use of TSMD. A search of the Archives of the Quality Indicators of Assistive Technology (OIAT) Listserv with members who are AT providers (AT specialists, speech/ language pathologists, occupational therapists, physical therapists, and special education teachers) vielded more than 2,000 messages, posted from February 14, 2010 through July 16, 2011 (Newton & Dell, 2011). The authors state, "these posts strongly suggest a great deal of interest in the iPad among AT providers" (p. 47). There is also growing interest in research on the role of TSMD in supporting learning for students with disabilities and the practical steps required to implement TSMD in special classrooms to support both learning and socialization. In the year 2013 alone three literature reviews were published and a review of doctoral theses found 117 theses on the topic of TSMD and developmental disabilities (Bradshaw, 2013; Kagohara et al., 2013; Knight, McKissick, & Saunders, 2013). For example in one of these theses Pelangka (2011), found that the ability to sustain attention on an independent

task of all child participants increased throughout the study and remained so during follow up. The parents reported satisfaction with the outcome of their child's ability to sustain attention on the TSMD, to remain functionally engaged with the device in various settings. and to manifest appropriate behaviors and non-maladaptive behaviors while engaged in tasks with the device. In general, the research suggests that technology-based interventions can provide increased opportunities for students with disabilities to acquire important academic and functional skills

TSMD are applied in the rapeutic and educational settings. Studies that have been published tend to be primarily qualitative and anecdotal. These studies concern TSMD as an instrument: to improve learning (Burton, Anderson, Prater, & Dyches, 2013); to strengthen communication skills (Fisher, Lucas, & Galstyan, 2013); and to improve social behavior (Hourcade, Bullock-Rest, & Hansen, 2012) and often simply as a leisure and play tool (Verenikina & Kervin, 2011). They show that this technology is useful in improving the play skills of children and in enhancing social, communicative, and language development (Murdock, Ganz, & Crittendon, 2013; Ploog, Scharf, Nelson, & Brooks, 2013). Reports have recounted that TSMD intervention strategies not only have helped children diagnosed with attention deficit hyperactive disorder (ADHD) focus

attention, they have also facilitated much more metacognitive aspects in the reading process (McClanahan, Williams, Kennedy, & Tate, 2012). TSMD may improve motivation and help children focus attention.

The information that is available from the relatively few research studies published is predominantly positive; however the data is very limited. In Knight et al.'s study (2013) the authors reviewed papers published between 1993 and 2012 to determine the degree to which new technology-based interventions could be considered an evidence-based practice. They found only 25 studies that met inclusion criteria for quality or acceptable studies. Of these, three were single-subject studies. A systematic review (Kagohara et al., 2013) of TSMD studies yielded 15 studies which reported outcomes for 47 participants, who ranged from 4 to 27 years of age and had a diagnosis of autistic spectrum disorder (ASD) and/or intellectual disability (ID). The results of studies were largely positive, suggesting that mobile technology offers viable technological support for individuals with developmental disabilities (DD). Bradshaw (2013) conducted a review of recent research on barriers concerning the use of such technology and found that new technology may not always be the best solution for all people with complex communication needs. There is a great deal of variation in the people with complex communication needs and much greater attention to individual characteristics and differences is needed in order to make decisions about who will benefit most from the new technology and what devices and applications are best suited to individual needs. As TSMD technology provides a highly flexible platform, we expect that as new special applications are developed the technology will meet a wider range of individual needs.

Our review of this literature raises several points which should be noted: First, taken together, the results of the various studies suggest that TSMD technology may have positive effects on developing play skills, strengthening social behaviors, reading improvement and other academic accomplishments. Yet, in general, practitioners should use caution when applying technologybased interventions (Knight et al., 2013: Newton & Dell, 2011). Researched benefits of TSMD technology in the home and at school are at the infancy stage. There is a merging of the worlds of education, disability and technology. The more students become familiar with using technology and teachers and parents gain greater access to it, the actual advantages and limitations of this tool will become evident (Aronin & Floyd, 2013). No single technology meets the needs of all children and the literature advocates an integrated use of various methods. Incorporating a variety of available technologies can alleviate some of the challenges of developing communication and

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literacy skills in an integrated process. A balanced approach is critical at home and in school for successfully developing the skills of students with significant disabilities (Carnahan, Williamson, Hollingshead, & Israel, 2012).

The great majority of the studies relate to the use of TSMD within the school setting. Far less concern is exhibited for the use of this technology at home. There is a need for studies that examine the experience of parents and siblings of children who use TSMD in the home from the perspective of the family. The present study investigates the experience of parents of children with DD and of typically developing children who use TSMD.

Social Participation

Social participation is an indicator of life quality and overall functioning. Findings presented by Lau, Chow and Lo (2006) indicate that children with different disabilities and chronic illnesses need help in restoring their quality of life to the standard experienced by their healthy peers, particularly in relation to psychosocial aspects such as social functioning, emotional functioning, and school functioning.

Children with physical disabilities were found to have an increased risk of limitation in participating in everyday activities (Lau et al., 2006). In a sample of youths with DD, Altshuler,

Mackelprang, and Baker (2008) found individuals who exhibited high levels of self-esteem self-satisfaction academic achievement, and overall resiliency and vet reported feelings of social isolation and higher levels of individual risk-taking behaviors. Shattuck, Orsmond, Wagner, and Cooper (2011), using a nationallyrepresentative sample of adolescents with ASD, reported findings which indicate that half experience no or very limited social activities with friends Many adolescents and young adults with DD become increasingly isolated. Research studies have identified and described social participation factors that affect persons with DD. Different challenges have been associated with different disabilities of young persons with DD (Kang et al., 2010; Law et al., 2006; Liptak, Kennedy, & Dosa, 2011). Those with ASD, for example, were found to have fewer experiences with their friends outside of school and were three to five times more likely never to get together with friends compared to groups of peers with other disabilities (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Shattuck et al., 2011; Solish, Perry, & Minnes, 2010).

Impact on the Family

Parents grieve the loss of their child not experiencing the accomplishment and joys so meaningful to most young people, i.e., having good friends, playing team sports, graduating from school, getting a good job, and having a family of their own (Lainhart, 1999). The pervasive and severe social problems often experienced by children with disability are associated with difficulties in family functioning including decreased parenting efficacy. increased parenting stress, and an increase in mental and physical health problems compared with parents of TD children (Karst & Van Hecke. 2012). Lainhart (1999) indicates that rates of major depression and social phobia are increased in first-degree relatives of children with DD and there is a high incidence of anxiety disorders and severe grief reaction found in family members. However, while researchers have collected much data quantifying the experience of families of children with ASD and other developmental conditions from a professional viewpoint, families have not had much opportunity to tell their own story from their family perspective (Schall, 2000). The professional viewpoint deals with the pervasive and severe symptoms often experienced by children. The familycentered perspective viewpoint is more often focused on the struggle with financial strains, time pressures, high rates of marital discord and lower overall family well-being (Karst & Van Hecke, 2012; Lainhart, 1999).

The present study adopts a 'family-centered' approach from the health-care field (Shelton, Jeppson, & Johnson, 1987), which advocates activities to enhance all family members' capacities

to carry out their self-determined roles (Dunst, 1990: Dunst, Trivette, & Deal, 1994). A family-centered philosophy defines parents as active partners and recognizes parental centrality in the lives of their children with disabilities (Mahonev et al., 1999; Neikrug, Roth, & Judes, 2011). Involving parents as partners with professionals has been shown to be a very effective method in promoting generalization and maintenance of skills in children with developmental disabilities (Ingersoll & Dvortcsak, 2006). There is a growing body of evidence that validates many of the links between a family-centered focus and desirable outcomes for families with a child with a disability (Dempsey & Keen, 2008). However, despite its well-established benefits, few public school programs include parent training as part of the childhood special education curriculum (Ingersoll & Dvortcsak, 2006; Ingersoll & Gergans, 2007).

This study surveys the experience of parents of children with and without developmental disabilities who use TSMD with particular interest in the parents of children with disability. Their subjective evaluation of its impact on their child's growth and development, and the quality of family life is important to understand especially when the family-centered approach is utilized in educational and therapeutic programs.

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Methods

Participants

This study included 69 respondents. Of these, 39 were parents of CWDD in Israel who use TSMD technology and 30 were parents of TDC who use TSMD technology. All respondents volunteered.

Instrument

The authors developed a survey questionnaire based on the review of TSMD literature. The questionnaire was designed to be used as a selfadministration instrument appropriate for electronic distribution. The instrument was reviewed by a panel of professionals who are experts in the use of TSMD technology with children with disabilities. The resulting survey includes an explanation of the purpose of the survey for the responding parent, the assurance that their anonymity would be preserved and that by responding to the survey they would be expressing their consent to the use of the data. In the first section the parents are asked to describe the characteristics related to their child's primary disability, as well as additional or secondary difficulties and challenges.

The survey includes 23 items, some of which have sub-items. For example, when asked if the child is using TSMD applications to improve communication; writing; reading, the parents could respond with a yes/

no response for each of the skills. Responses to the items were either ves/ no or a 5-point Likert type scale, with the lowest, i.e. 1 "extremely little" and the highest, i.e., 5 "extremely high". The items related to four domains: 1 Parents' support needs for example "How pleased are you from the support and guidance you received in using the TDSM with your child?": 2. Parental involvement with the child for example. "How do you see the level of involvement you have with your child in using the TSMD?"; 3. Parental goals for the TSMD. for example, "Do you have specific goals for using TSMD with your child?": and 4. Parental evaluation of the TSMD experience, for example "How satisfied are you with changes which occurred with your child due to TSMD use?". Each domain had three items except for the domain of parental evaluation that had four items. Several open questions relate to specific aspects of the respondents' experience with TSMD technology. For example information regarding the applications used, and what caused or who made the final decision to purchase the device.

In the development of the instrument there was no attempt to analyze the factor structure or the internal consistency of the items. The items are based on the theoretical dimensions in the literature. The final survey instrument was pretested on a panel of parents not included in the study in order to determine the degree to which the items were clearly understood and coherent

Procedure

Anonymity and confidentiality were protected by the following arrangements: respondents were invited to participate in the study via organizational websites where they could download, complete, and send the questionnaire. The study was approved by the Helsinki Committee at Ariel University and the ethics committee at Beit Issie Shapiro.

Parents of CWDD were approached through various internet forums and parent organizations and if they chose to participate in the study they were offered a web site where they could download, complete, and send the survey electronically. Parents of TDC were approached through friendship circles of the researchers thus, it is a convenience sample. No identifying information was asked on the survey forms.

The major disabilities and challenges of the child using TSMD technology according to the parents' report are summarized in Table 1.

Table 1
Children's Diagnosis and Challenges as Reported by Parents*

Diagnosis & challenges

Autism Spectrum Disorder (including PDD)	n=22
Intellectual Disability	n=6
C.P.	n=5
Behavioral Problems	n=14
Emotional Problems	n=13
Speech and Language	n=14

^{*} Some reported more than one diagnosis or challenge

Data Analysis

All statistical analysis was conducted using SPSS-21. An independent sample t-test was administered to compare the two groups surveyed, i.e., parents of CWDD and parents of TDC. Pearson's correlation coefficient was administered to examine the relationship between the parental domains and the parent's perception of the child's performance on the TSMD.

Results

Parent's Satisfaction Domain

The findings of this study focused on gaining an understanding of the parents' perception of their child's experiences with mobile technology and the main correlates of parental satisfaction. In general this study found a fairly high mean score for satisfaction in the TSMD experience domain among the parents of CWDD (M=3.47, SD=1.17) and somewhat less satisfaction among parents of TDC (M=3.13, SD=1.36), within a statistically significant range of p<.01-.001. Thirty percent of the parents of CWDD were highly satisfied and 16.7% were very highly satisfied with the children's use of TSMD As expected, we found that general parental satisfaction was positively correlated with improvement in the child's positive social interactions: these included the child's interaction with teachers and therapists (r=.46, p<.05), the child's relationship within the family (r=.59, p<.001), the child's relationship with peers (r=.46, p<.05), and the child's positive interaction with other adults (r=.37, p<.05).

Parent's Goals Domain

The parents of CWDD had clear goals for their child's use of the TSMD

technology (M=3.56, SD=1.19), Only 10% answered they had no (or hardly any) specific goals. The the parents' goals were fairly equally divided between considering the technology a leisure activity, a tool for improving communication skills, a way to improve relations with child's peers, as well as, a general expectation that the technology would contribute to the child's development and be useful for school work. Specific academic skills (reading, writing, etc.) were not indicated as the main value of the technology. On the other hand, 70.9% of the parents of CWDD felt that the experience had a positive effect on the child's acquisition of new general information

Based on Pearson's correlation coefficients, highly positive and significant correlations were revealed between parents of CWDD who had clear goals for their child's use of the TSMD and parents' general satisfaction (r=.67, p<.001), the child learning new information (r=.76, p<.001), the degree of parental involvement (r=.57, p<.05), and the degree to which parents felt comfortable with the TSMD technology (r=.54, p<.001).

Parent Involvement Domain

A third area of inquiry concerns the degree of parental satisfaction with the improvement in the child's and the parents' own involvement. The parents' perception of the child learning new information with the TSMD was associated with the parent's involvement in the child's TSMD experience (r=.49, p<.01). Likewise. we found a high positive correlation between parental satisfaction with the child's relationship within the family and the degree to which the parent was involved in the child's TSMD experience (r=.66, p<.001). Parents who were computer literate and comfortable with the technology correlated positively moderately in their involvement with their children's experience with TSMD (r=.39, p<.05). Furthermore, parental involvement was positively correlated with the child's improved interaction with teachers and therapists (r=.47, p<.01), and positive interaction with peers and with adults in general (r=.41, p<.01). Moreover, notably, we found that the degree to which the parent was involved with the child's TSMD experience was highly correlated with the parents' reported quality of family life (r=.51, p<.01).

Preparation and Support Domain

The parents of CWDD expressed low satisfaction with the preparation that they received for the use of this new technology (M=2.16, SD=1.07) and with the support and instruction that they received during the experience (M=2.12, SD=1.16). When an open question was posed: "From whom did the family receive assistance in purchasing the TSMD and its applications?", 40% of the parents responded that they had not received any assistance and 10% indicated that they received advice from the

store sales persons. The remainder indicated that they received advice from friends, family, colleagues and the internet. When asked about the degree of their satisfaction with the support and instruction they received after the purchase, only 17.2% indicated positive satisfaction and 35% indicated extreme dissatisfaction. The parents' referred to the school, family members, internet resources, and other parents, as those to whom they approached for support.

Preparation and support were found to be strongly and positively correlated to the child's improved social performance, (r=.50, p<.05) as well as to the child's ability to learn new information (r=.45, p<.45). We found that support and preparation received by the parent was positively correlated with the degree to which the parent was involved in the child's TSMD experience(r=.39, p<.05).

Differences between Parents of Typically Developing Children and Parents of Children with Developmental Disabilities

The information received from the parents of TDC differed in several dimensions from information received from parents of CWDD. Independent t-tests were performed to determine the significance of the differences found between the two groups. When asked about the degree to which they had specific goals for their child's use of the TSMD technology, 36.7% of

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parents of TDC answered that they did not have any (or hardly any) specific goals and only 13.3 % indicated that they had specific goals. This differs significantly from the parents of CWDD who indicated that they had specific goals (56.3%), and that the goals were fairly equally divided between the leisure activity, game playing, and a tool for communicating with friends. The responses of parents of TDC were significantly lower (M=2.80, SD=.94) than of parents of CWDD (M=3.84. SD=1.34) on the value of the TSMD for the child learning new information (t=3.42, p<.01). The degree of parent involvement was higher for the CWDD group (M=3.70, SD=1.29) compared to the TDC group (M=2.87, SD=1.29, t=2.28, p<.05).

Significantly higher mean responses to the questions regarding the child's improvement in relationship to parents, teachers, professionals, other children and adults in general were received from parents of CWDD (M=3.11, SD=1.31) compared to parents of TDC (M=2.13, SD=1.13, t=3.01, p<0.01). This may be due to parents of TDC having less expectations of change in these areas and/or typically developing children having fewer problems in these areas.

In two areas we found similar dissatisfaction among TDC and CWDD parents: 51.7% of the parents of TDC and 56% of parents of CWDD were extremely dissatisfied with the assistance that they received from professionals in

the choice of the technology; 55.2%, compared to 64%, respectively, were dissatisfied with the support that they received from professionals after purchasing the devices. Interestingly in both findings regarding the assistance that they received, parents of TDC showed significantly less dissatisfaction compared to parents of CWDD.

Discussion

This study, while limited by a small and self-chosen sample, allowed us to gain insight into a number of questions concerning parents' experience with TSMD technology. In general in this study we found a fairly high level of satisfaction with the results of the TSMD experience among parents of CWDD Parental satisfaction correlated highly positively with several parameters that give insight into the nature of the experience. i.e., having clear goals, perceived improvement in the various disability related areas, parental involvement, support, and supervision. Parental satisfaction correlated positively with TSMD being a tool that enhanced the child's social skills and the ability to successfully interact with others. Parents had higher satisfaction when they perceived improvement in their child's behavior at home, in school and with friends. From their perspective, the ability of TSMD to improve academic achievement is related to a holistic desire to see meaningful changes

in the child's behavior in all critical areas. Parents who are technologically confident are more capable of helping the child enhance his or her experience with the new technology; they are more involved and are more satisfied.

It is in this light that we understand the high degree of dissatisfaction that parents of CWDD indicated with the preparation, ongoing support and supervision that they received in using TSMD technology. Most parents are less than fully technologically confident. They are dependent on professional support services which, according to the parents, are unavailable or inadequate. Perhaps the parents of TDC view the device as an educational toy and have less expectations of receiving assistance while parents of CWDD view the devices as a therapeutic aid and expect to receive assistance from professionals so that their child will attain the maximum benefit from the devices

There is a clear need to help parents improve the quality of their children's experience at home. Zablotsky, Boswell, and Smith (2012) reported that in a national sample of families (N=8,978) a significant positive correlation was found between parental school involvement and parental school satisfaction. They found that parents of CWDD were more likely than parents of TDC to attend parent-teacher conferences, meet with school guidance counselors, and help the child with homework. In this study we also found that parents of CWDD were also more dissatisfied with the

level of communication provided by the school

These findings have important implications for how professionals interact with and support families with CWDD Parental involvement is related to the child's improved behavior and ability to learn. We found that the greater the extent to which the parents are involved with the child using TSMD technology the greater the child's success in the relevant areas of child improvement. Parents require support and supervision to clarify and evaluate goals. Support and supervision give the parent the confidence to work with the child and share the TSMD experience. Support and supervision given to the parent not only improves confidence, but assists the parent in clarifying specific goals for the child's development, ensures that more appropriate hardware and more individualized software are chosen, all of which are necessary for maximum success

The importance of professional support services and parental involvement has been emphasized in previous studies, which indicate that increases in parents' involvement over time were related to concomitant increases in children's social skills and a reduction in problematic behavior (El Nokali, Bachman, & Votruba-Drzal, 2010).

More research is required to deepen our understanding of the relationship between parental involvement and parental satisfaction with TSMD, and

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to clarify whether parental satisfaction is related to actual and objective improvements in children's social skills and a reduction in their problematic behavior

Limitations

Several limitations in the findings of this study should be noted. This study was based on a very small number of respondents who were not randomly sampled and the lack of representation greatly limits the ability to generalize the findings. Larger scale research based on a representative sample is necessary in future studies. Our emphasis on parental satisfaction is limited to their subjective experience and cannot be taken as an objective measure.

Nonetheless, our convenience sample does provide some initial data that can be helpful in understanding the experience of the families. Notwithstanding, numerous questions must be raised in further research. For instance: What are the challenges that parents have to overcome in working with TSMD? What are the problem solving strategies used to solve these issues? How do parental perceptions compare to the perceptions of teachers and therapists? More information is needed to clarify the changes parents note in the children's interaction with parents/peers/teachers/helping professionals and other adults after using TSMD technology. Further research should expand our inquiry into the effects of this new technology on family quality of life as a whole.

Conclusions

To date relatively little has been studied about the experience or perceptions of parents relating to their child's use of TSMD. This is a preliminary study to understand the value of the new technology for children with disabilities from the parents' perspective. Parents face many challenges in trying to provide the best care for their child. They must navigate the complex healthcare, social support and educational systems. Much of their energy, hopes and prayers are centered on finding the right intervention that may not cure their child but offers the promise of their leading a more "normal" family life. However, most studies on children with DD concentrate on child outcomes, ignoring parent and family factors.

Children with disabilities face many challenges in achieving their potential, including difficulties with social interaction, communication. flexibility of thought and anxiety management. TSMD technologies offer a non-stigmatizing tool that could be used to complement existing support strategies to aid the child with disabilities and the family to improve communication, social interaction, anxiety reduction, relaxation, reward, and motivation. The literature has just begun to evaluate the potential advantages that the recent explosion of interest in and proliferation of TSMD pose for children and their

families. This study offers findings to support considerable parent satisfaction with the new technology. Further research will clarify if this satisfaction will continue over time

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