

Self-Management for Autism Spectrum Disorders: A Review

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Autism Spectrum Disorders (ASDs) could cause severe and pervasive impairment in thinking, feeling, language, and social functioning. Self-management has the potential to empower autistic individuals by teaching them skills that will improve their independent functioning and quality of life. We described six studies which utilized different tactics for self-management for children with ASDs, and summarized the findings from these studies.

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INTRODUCTION

Autism Spectrum Disorders (ASDs) are a collection of heterogeneous neurodevelopmental conditions that result in varying degrees of early-onset challenges in social communication and interaction, and restricted, repetitive behavior and interests.¹ While there are various risk factors correlated with the development of autism, none of them are completely necessary or sufficient alone.¹ Over the past two decades, there has been a dramatic increase in the prevalence of ASDs in school-age children.¹ Worldwide ASDs now affect around 1-2% of the school-age population.²

While what causes autism is not clear, the effects of autism have been well documented. Not only do individuals with autism have a 2-8% higher mortality rate than non-autistic individuals of the same age and sex, but without early intervention, 58-78% of adults with autism have poor to very poor outcomes in terms of independent living, educational attainment, employment, and peer relationships.¹ Although a small minority of autistic individuals may achieve normal to high levels of functioning, 75% of autistic individuals are mentally retarded.³ Parents of autistic children often struggle with added child-care burden as their children require increased attention and aid with daily living skills.⁴ Teachers or health care professionals working with autistic children in a school setting often have to spend copious amounts of time and energy managing and preventing disruptive stereotypic behavior commonly associated with autism.² Additionally, as autistic individuals transition into adulthood and out of education programs, many of them struggle without the support and mental health services offered by such programs.¹ Financially, children with autism cost caretakers,

and the healthcare and education systems much more than non-autistic children.⁵ In the United States in 2011, societal costs of school-aged children with ASDs added up to 11.5 billion, with an autistic child costing an average of \$17,081 more per year than a non-autistic child.⁵ Additionally, autism takes a toll on the ability for autistic individuals to be employed. On average, only 46% of adults with autism are employed, or enrolled in full-time education.¹

Management of Behavioral Problems Associated with ASDs: One of the main criteria for the diagnosis of autism is the presence of stereotypy (A.K.A. self-stimulation), a collection of chronic, repetitive behaviors that are maladaptive and disruptive.⁶ Some types of stereotypy include body rocking, hand flapping, and bizarre vocalizations.⁶ The most widely used strategies for managing behavioral challenges associated with autism involve antecedent or consequent events imposed by a parent, teacher, or therapist.⁶ These strategies include reinforcement-based procedures involving differential reinforcement of alternative behavior, increasing the amount of effort required to engage in stereotypy, decreasing the sensory input produced by stereotypy, or punishment-based strategies like overcorrection and response blocking.⁶ While these strategies have been shown to be effective, they focus more on the external control of problematic behavior than on helping students gain the skills needed to self-regulate their own behavior and function more independently.² These interventions are also intrusive and take up a lot of time and resources as caretakers or teachers need to constantly apply external contingencies rather than attend to other important matters or teach.² With an increasing prevalence of ASDs and the burden that the disorders place on autistic individuals, caretakers, and society, new strategies that focus on helping autistic individuals self-manage their own behavior need to be developed, evaluated, and applied.

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SELF-MANAGEMENT OF ASD

Self-management involves the methods, skills, and strategies used by individuals to direct their own behavior and achieve specific goals. Goal setting, planning, scheduling, task tracking, self-evaluation, self-intervention, and self-development are all effective self-management strategies.⁷ In health care, patients who suffer from a disease or chronic condition may improve their quality of life and manage their illness through self-management training, skill acquisition, and interventions. Self-management strategies have been successfully used to manage many chronic illnesses including diabetes, congestive heart disease, and obesity.⁷

Self-management can be an effective technique to manage behavioral problems associated with autism. Effective self-management techniques involve a collaborative relationship between the autistic individual and one or more caretakers, teachers, or clinicians. In the process of learning to self-manage their symptoms, autistic individuals are trained and encouraged to 1) view treatment as a collaborative process, 2) actively self-monitor symptoms, and 3) supplement professionally-delivered interventions with evidence-based, self-administered interventions.⁷ Self-management has the potential to empower autistic individuals by teaching them skills that will improve their independent functioning and quality of life. Self-management training for autistic individuals can also increase access to treatment for individuals in geographically-remote areas as learned skills can be applied without the presence of providers. Also, by teaching patients ways in which they are able to manage their own symptoms, clinician time may be reduced, thus enabling clinicians to treat additional patients. Finally, self-management has the potential to reduce the financial burden of autism including healthcare expenses and lost workplace productivity by enabling autistic individuals to utilize the skills they have acquired to function better and achieve more.

The purpose of this paper is to review and summarize relevant studies on the efficacy of various self-management techniques for the treatment of ASDs. Using self-management techniques to treat ASDs is a relatively new concept, but the literature on the topic is continually emerging. Out of around 20 studies, we have selected 5 case studies and 1 randomized controlled trial that demonstrate a variety of applications and levels of efficacy of self-management in the treatment of ASDs. Some studies assessed the effectiveness of self-monitoring, self-recording, and self-reinforcement in increasing appropriate behaviors and decreasing self-stimulating/inappropriate behaviors in clinical (Koegel et al., 1992) and generalized (Stahmer & Schreibman, 1992) settings.^{8,9} Others examined the role of self-recording in decreasing stereotypic behaviors when used in conjunction with instructional control or differential reinforcement.⁶ Pierce & Schreibman (1994) reported on the effectiveness of using pictorial self-management to teach autistic children to independently perform daily living skills.⁴ D. K. Mithaug and D.E. Mithaug (2003) compared the effectiveness of teacher-directed versus student-directed instruction in increasing adaptive behaviors through self-

management.¹⁰ Lastly, Chan et al (2013) investigated the efficacy of teaching a Chinese mind-body exercise to autistic children as a self-management technique to increase self-control.¹¹

Study 1: "Improving Social Skills And Disruptive Behavior in Children With Autism Through Self-Management" (Koegel et al, 1992).⁸

Children with autism typically do not respond to verbal initiation from others, or respond with disruptive, avoidance-driven behaviors.⁸ Because of that, it is hard for autistic children to socialize, communicate, and integrate with mainstream society. In order to successfully interact and exist with other people, children with autism need to be able to self-manage disruptive behaviors, and respond to others appropriately.

Koegel et al. conducted this study to assess whether self-management could be used as a technique to produce extended improvements in responsiveness to verbal initiations from others and decrease disruptive behaviors during social interactions in community, home, and school settings without the presence of a treatment provider. They studied 4 male children diagnosed with autism that were reported as responding to others' verbal initiations with either unresponsiveness, despite having appropriate language development levels, or with disruptive behavior. Two of the children were around 7 years old while the other two were around 11 years old. The composite IQ scores of the 4 children, as measured by the Stanford-Binet Intelligence Scale (SBIS), were 58, 58, 74, and 85, with scores of 90-109 classified by the fifth edition of the scale as average in the general population.¹² Cultural information on the subjects was not provided. The study was conducted in a variety of settings depending on the subject, ranging from clinic, community, home, and school settings. As a case study with a small sample size, this study needs to be replicated on a larger scale in order to generalize and support findings.

These four children were taught self-management techniques that trained them to become aware of when they were engaging in appropriate or inappropriate behavior, and to regulate such behavior. They were first taught to discriminate between appropriate and inappropriate behavior. They were then trained to give themselves points for appropriate behaviors, like responding to someone's question, and to not give themselves points for inappropriate behaviors, like stereotypic behavior. When they reached a certain number of points, the children were trained to reward themselves.

The researchers found that self-management procedures were successful in increasing social responsivity and decreasing disruptive behavior in autistic individuals. These improvements persisted in the children's natural environments, without the presence of a treatment provider. These findings have positive implications for the use of self-management to treat ASDs by helping autistic individuals

socially interact with others, and integrate into mainstream society.

Study 2: “Teaching Children With Autism Appropriate Play In Unsupervised Environments Using A Self-Management Treatment Package” (Stahmer & Schreibman, 1992).⁹

In this study, Stahmer and Schreibman pointed out that while a variety of treatment strategies have been reported to be effective in teaching appropriate behaviors to children with autism, these strategies require the continued presence of a treatment provider. This requirement limits the generalizability of the treatment effects for these children. If autistic children were able to provide their own treatment while unsupervised, they would increase their ability to function independently, and decrease the amount of supervision they require.

Stahmer and Schreibman examined whether the use of self-management techniques would increase appropriate play and decrease self-stimulatory behaviors in children with autism. The researchers recruited 3 children with autism (2 male, 1 female) that displayed inappropriate toy play when unsupervised, and that exhibited self-stimulatory behavior when playing with toys. The children were aged 7, 12, and 13, with IQs of 43, 46, and 65 as measured by the SBIS. Cultural information on the subjects was not included. The study was conducted in clinical and home settings. As a case study with a small sample size, this study needs to be replicated on a larger scale in order to generalize and support findings.

The three children were first taught to discriminate between appropriate behavior and inappropriate behavior during play. Children were then taught to cue a time interval during which they were supposed to display appropriate play. They used self-monitoring sheets to record whether or not they had displayed appropriate behavior. If the time interval passed without the display of any inappropriate behavior, they were rewarded.

The researchers concluded that self-management increased appropriate play and decreased self-stimulatory behaviors in the autistic children. These increases were maintained while the children were unsupervised, and in various settings. Such improvements were maintained for 2 of the children 1 month after the last training session, while 1 child needed a booster session, after which he quickly recovered those improvements. Not only do the findings of this study support the notion that self-management training can increase the independence of autistic children, but they also provide a way for the children to get involved with their own treatment. This may increase autistic children’s engagement in and responsiveness to treatment.

Study 3: “Analysis of Self-Recording in Self-Management Interventions for Stereotypy” (Fritz et al, 2012).⁶

As discussed earlier in this article, one of the main criteria for

the diagnosis of autism is the presence of stereotypy.⁶ Many studies have looked into how to reduce stereotypy in autistic individuals because stereotypy consists of behavior that is maladaptive and disruptive.⁶ A small body of research, like the studies done by Koegel and Koegel (1990) and Shabani et al (2001), has begun to emerge that suggests that self-recording, a type of self-management intervention, is effective in decreasing stereotypy.^{13,14} However, Fritz et al. questioned whether the decrease was due solely to self-recording, or whether instructional control, and differential reinforcement of other behavior were responsible for the results, as those were all components of the self-management interventions employed in the earlier studies.

Fritz et al. conducted a component analysis to examine what variables were responsible for producing the reductions in stereotypy in the autistic individuals observed in Koegel and Koegel (1990) and Shabani et al (2001).^{13,14} The researchers studied 2 adult males (ages 40, 49) and 1 male child (age 12) that had been diagnosed with autism and engaged in stereotypy frequently throughout the day. Subjects were included in the study if results of a functional analysis showed that their stereotypy was maintained by automatic (sensory) reinforcement. Information on the subjects’ levels of intellectual functioning and culture was not included. The study was conducted at the day programs or schools that the individuals attended. As a case study with a small sample size, this study needs to be replicated on a larger scale in order to generalize and support findings.

Fritz et al. offered the same self-management interventions described by Koegel and Koegel (1990) and Shabani et al. (2001).^{13,14} Autistic individuals were first trained to discriminate between the occurrence and non-occurrence of stereotypy. They were then taught to indicate whether stereotypy did or did not occur during a specific time period on a self-recording sheet. If the autistic individuals recorded accurately, they received a reward.

Fritz et al. concluded that decreases in stereotypy may be due to instructional control or to differential reinforcement of other behavior, but that self-recording has little effect on decreasing stereotypy. These findings suggest that for some autistic individuals, self-recording is not an effective technique to decrease problem behavior. It can also be concluded that more effective self-management techniques to decrease problem behavior should be looked into, and that self-recording may be more effective when used in conjunction with other treatments than when used alone. However, it should be noted that while this study finds that self-recording does not play a strong role in decreasing disruptive behavior, it has been used successfully to increase or maintain adaptive behavior in individuals with intellectual disabilities, as can be seen in study 2.⁹

Study 4: “Teaching Daily Living Skills To Children With Autism In Unsupervised Settings Through Pictorial Self-Management” (Pierce & Schreibman, 1994).⁴

One of the main factors that make caring for an autistic child very challenging is the child's lack of autonomy. Caretakers of autistic children need to spend increased time and attention on guiding their offspring through daily living skills, like getting dressed, or making a bed. If autistic children were able to achieve daily living skills independently, they would be more likely to thrive in both domestic and vocational situations. Prior studies have shown that using pictorial self-management techniques, in which pictures are used to prompt individuals to initiate a certain action or sequence of actions, has been effective in guiding the behavior of adolescents or adults with disabilities.⁴ However, Pierce and Schreibman wanted to look into the effectiveness of pictorial self-management on guiding the behavior and developing the complete autonomy in daily living skills of autistic children.

Pierce and Schreibman examined 1) whether pictures could be used effectively in conjunction with elements of a traditional self-management treatment package, 2) whether pictures as prompts were effective self-management tools for severely delayed autistic children while not in the presence of a treatment provider, 3) whether the use of pictorial self-management could be generalized across a range of behaviors and settings, 4) what the extent of the pictures' stimulus control was, 5) whether this self-management technique would result in changes in other (non-target) inappropriate behavior, and 6) how long such behavior change was maintained. The researchers studied 3 autistic boys (ages 6, 8, 9) who had limited expressive language skills and required constant supervision. The participants achieved Peabody Picture Vocabulary Test standard scores of <20, <20, and 32, which is equivalent to the performance of an average 2-4 year old. Participants' cultural information was not given. The study was conducted in clinical and home settings. As a case study with a small sample size, this study needs to be replicated on a larger scale in order to generalize and support findings.

Pierce and Schreibman used traditional elements of self-management, including self-selection of reinforcers, self-monitoring and evaluation of performance, and self-delivery of reinforcement. They used pictures as antecedent stimuli to teach daily living skills. Pictures that depicted different steps necessary to complete a task were printed and made into booklets that were given to the children. The children were taught to discriminate what step in a task each picture represented. The children were then taught to perform the actions depicted by each of the pictures, and to turn the pages of the book to see what the next steps were. If the children reached the end of the book, they were allowed to reward themselves.

Pierce and Schreibman found that children with autism could successfully use pictures to manage their behavior in the absence of a treatment provider, and that that behavior could be generalized across settings and tasks, and maintained after the training ended. Additionally, all children showed a

substantial decrease in stereotypic behaviors, showing that by teaching autistic children appropriate behavior, inappropriate behaviors will decrease. The study also found that pictures could stimulate and control the children's behavior. Not only that, it was also observed that the time it took to learn to self-manage different behaviors decreased as experience with self-management increased. These results suggest that pictorial self-management can be a powerful tool for helping autistic children become self-sufficient in many different settings, and can therefore help to reduce parental burden.

Study 5: "Effects of Teacher-Directed Versus Student-Directed Instruction on Self-Management of Young Children With Disabilities" (D. K. Mithaug and D.E. Mithaug, 2003).¹⁰

A handful of studies have shown that self-management techniques can be effective in helping autistic children increase adaptive behaviors, like doing school work.¹⁰ However, more research needs to look into how to most effectively provide self-management training for autistic students. Would it be more effective to have teachers model self-management skills, or to have autistic students try to implement those skills themselves?

In this study, Mithaug and Mithaug considered the importance of the student-directed component of self-management training and examined whether independent goal setting, self-monitoring, and self-evaluation were higher after student-directed instruction than after teacher-directed instruction for autistic students. The researchers recruited 4 disabled 5-6 year old children (1 girl, 3 boys) from a school for young children with severe learning and behavior problems: 2 diagnosed with ASDs, 1 with ADHD, and 1 with emotional disturbance. 2 of the participants could identify a few words and count to five, while the other 2 participants could read and count at a kindergarten level. None of the students could work independently before the study. Cultural information on the subjects was not provided. The study was conducted in a classroom setting. As a case study with a small sample size, this study needs to be replicated on a larger scale in order to generalize and support findings.

Each day, teacher- or student-directed instructional sessions were conducted in the morning, while independent work sessions were conducted 2 hours later. During teacher-directed instructional sessions, teachers exhibited self-management skills by setting goals, assigning work, and recording and evaluating results on a self-recording card for each student. During student-directed instruction, teachers prompted students to practice self-management skills by reminding them to set their own goals, assign work to themselves, and to record and evaluate their results on their self-recording cards. If students met their set goals in either of the two conditions, they were rewarded. During independent work sessions, students were then left alone to see whether or not they would continue to exhibit self-management techniques without prompting.

The researchers concluded that students showed a higher number of independent self-management responses following student-directed instruction than following teacher-directed instruction. This suggests that in teaching autistic children self-management techniques, it is more effective to have the children try to direct their own self-management behavior, than to have an external source model self-management behavior. This is positive as the former, more effective approach also pushes autistic children to achieve a higher degree of independence.

Study 6: "A Chinese Mind-Body Exercise Improves Self-Control of Children with Autism: A Randomized Controlled Trial" (Chan et al., 2013).¹¹

One trait often associated with autism is executive dysfunction, or difficulties in working memory, attention, planning, response inhibition, mental flexibility, and/or self-monitoring.¹¹ This results in autistic individuals having difficulties learning, interacting with others, and living independently. As no effective pharmaceutical intervention has been discovered for executive dysfunction in autistic individuals, other techniques have had to be developed to help autistic individuals manage their behavior.¹¹ While a variety of behavioral and self-management techniques have been developed to help autistic individuals manage their behavior, the mind-body component of self-management techniques is still relatively new to the field. One example of a mind-body technique is Nei Yang Gong, which is a traditional Zen-based Chinese mind-body exercise that involves sets of slow, smooth, and calm movements.¹¹ The exercise is aimed to foster self-awareness and mental self-control to help restore a calm and relaxed state, reduce stress, increase flexibility of the limbs, and to improve the circulation of Qi (the traditional Chinese concept of an internal flow of energy) and blood.¹¹ Another mind-body technique is Progressive Muscle Relaxation (PMR). PMR is a well-established mind-body behavioral treatment that has been used to treat anxiety, physiological arousal, and emotional disturbances.¹¹ Although PMR is more widely recognized than Nei Yang Gong, the latter technique may hold more promise in the treatment of behavioral problems in autistic individuals.

In this study, Chan et al. performed a randomized clinical trial to compare the efficacy of Nei Yang Gong versus PMR in enhancing the self-control of children with autism spectrum disorders. The subjects consisted of 40 (36 male, 4 female) children diagnosed with ASDs between the ages of 6-17. The average IQ score as measured by the Chinese version of the Wechsler Intelligence Scale for Children-Fourth Edition or the SBIS was 79.43. While cultural/ethnic information was not explicitly stated, the subjects were presumably mostly Chinese as this study was conducted in Hong Kong, which, according to the 2011 census, has a population in which 93.6% of individuals identify themselves as ethnically Chinese.¹⁵ The study was conducted in clinical settings. While this study is a well-designed randomized controlled trial, it still suffers from a small sample size.

The children in the experimental group were taught to practice Nei Yang Gong, consisting of a tranquil stand, shoulder relaxation technique, nasal bridge massage, Qi-circulating movements, and passive Dan Tian breathing. They were also taught to practice Nei Yang Gong self-guided massages to relax and calm themselves if they felt distressed. These training sessions were taught in a specific sequence to music to facilitate learning. The children were encouraged to practice the movements 1-3 times daily. Children in the control group were taught the Chinese-version of the Progressive Muscle Relaxation (PMR) Technique. They were taught to sequentially tense and relax seven muscle groups as instructed by a sound track.

Chan et al. found that Nei Yang Gong enhanced self-control, and reduced typical autistic symptoms and daily emotional and behavioral problems of children with ASDs significantly more than PMR. Children who practiced Nei Yang Gong also showed significantly increased electrophysiological activity in the rostral anterior cingulate cortex, which mediates inhibitory control and is hypo-active in most individuals with ASDs, while children who practiced PMR did not show these gains. These findings suggest that Nei Yang Gong is a promising treatment for patients with self-control problems. They also show that mind-body treatments are effective self-management techniques that can be used to treat the behavioral problems associated with autism. In more severely mentally impaired individuals, mind-body strategies may be better than other self-management techniques as they may be easier to learn.

DISCUSSION

ASDs present challenges to autistic individuals, caretakers, and to society. Autistic individuals often struggle to function independently, and integrate into society (Koegel et al, 1992). Caretakers and teachers commonly need to spend more resources in terms of time, money, and energy on individuals with autism than on non-autistic individuals.^{2,5} In society, autistic individuals financially cost much more than people without autism.⁵ With the prevalence of autism on the rise, the need for treatment is growing. However, it is difficult to find treatment for children with autism.¹⁶ According to a national survey, one-third of children with autism had trouble accessing appropriate care, mostly due to difficulty finding providers with the appropriate training.¹⁶ Not only that, but many children with ASDs do not respond well to most currently offered "top down" approaches which involve the external manipulation of antecedents and consequences.² Therefore, it is evident that alternative strategies to treat ASDs need to be developed, examined, and applied.

Teaching people to manage and control their own behavior is an essential life skill. According to Alberto and Troutman (2009), each individual is the best person to manage his or her own behavior. Each person can only depend on him or herself to take care of themselves throughout their entire lifetime, and to know what type of reinforcement he or she will be most motivated by.¹⁷ This argument is supported by Mithaug & Mithaug's (2003) study which showed the

importance of the self-directed component in self-management techniques.¹⁰ With the evidence provided by the reviewed studies, self-management has been shown to be effective in targeting social unresponsiveness, disruptive behavior, inappropriate play, inadequate ability to perform daily living skills, stereotypy, inadequate self-control, and other disruptive autistic symptoms. Additionally, having a self-management program can promote a cycle of increasingly positive interactions.¹⁸ Therefore, in order to increase the independence and quality of life of autistic individuals, and reduce the burden on caretakers and society, self-management techniques should be used to supplement the current treatments of ASDs.

There are some limitations in the findings of the reviewed studies. Except for Chan et al. (2013), which was a randomized controlled trial with a small sample size (n=46), the studies examined around 3-4 subjects, mostly with short intervention and follow-up periods.^{4,6,8-11} These studies may be considered as case studies, which may have a bias in their case selections. Without a larger sample size and randomized controlled trials, such studies may generate interesting hypotheses but do not have solid evidence to support their hypotheses. The small sample sizes in all of the studies also limit the generalizability of their findings. Also, due to the lack of/ short follow-up periods, it was unclear whether subjects could successfully taper off the self-management materials and reinforcement offered during the studies, and maintain the results long-term.

Most of the self-management approaches (with the exception of Chan et al, 2013) will need to be culturally adapted and shown to be effective before they are used clinical among Chinese Americans with ASDs.¹¹ It should also be noted that the self-management techniques we have described in this review all involve a collaborative relationship between the autistic individual and one or more caretakers, teachers, or clinicians. This requires intensive training which is frequently hard to come by due to insufficient time, education, and resources. Furthermore, such positive outcomes for most of the self-management techniques described are only possible for children with less severe autistic symptoms, who are able to follow the rules and requirements of the training. However, the mind-body exercise reported by Chan et al (2013) offers an alternative treatment, with simple mind-body exercises that are described as easy to learn.¹¹ If replicated, mind-body exercises may provide inexpensive, widely available, and

effective treatment for patients with varying degrees of ASDs. More research is needed in the efficacy and effectiveness of using self-management as a treatment for ASDs, self-management techniques that are easier to implement and are applicable across the ASDs spectrum, and in the cultural adaptability of such results to minority populations.

CONFLICT OF INTEREST

None.

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