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A Community-Based Accommodation Program for Adults with Autism and Mental Retardation

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Abstract: There is a paucity of treatment literature for significant and intractable behavior problems in adults with autism and mental retardation. Four adults with autism, severe to profound mental retardation, and serious, long-term behavior problems participated in an accommodation training program as an adjunct to more traditional behavioral and medical treatments. The accommodation program consisted of designing highly structured and predictable daily routines to reduce the impact of environmental factors that had previously resulted in behavior problems. Following three to six years of participation in the accommodation program, a significant treatment effect size was obtained for all participants. The benefits of this approach for improving the treatment-resistant problem behaviors and quality of life for adults with autism and mental retardation in a community-based setting are discussed as well as directions for future research.

Autism and mental retardation commonly co-occur with approximately 75-80% of persons with autism also having varying degrees of mental retardation (Fombonne, 1999; Honda, Shimizu, Imai, & Nitto, 2005). Despite the finding that autism represents a life long disorder for most individuals, there presently exists a paucity of research on adults with autism (Brereton & Tonge, 2002). In a review of studies that have followed individuals diagnosed with autism into adolescence and adulthood, Seltzer, Shattuck, Abbeduto, and Greenberg (2004) found that only 15% had favorable outcomes. The most important predictors of positive adult outcomes were a relatively high IQ and the development of some form of communicative speech before the age of six years (Stein et al., 2001). Consequently, the prognosis for adults with autism and severe to profound levels of mental retardation remains

relatively poor. For these individuals with more significant intellectual impairments, behavior problems are common, impact the quality of their lives, and pose a significant challenge for staff members who care for them in residential settings and day training placements (Van Bourgondien & Elgar, 1990). These challenging behaviors may include stereotypies such as arm flapping, pacing, and body rocking, compulsive and ritualistic behaviors, noncompliance, disruptive behaviors such as repetitive vocalizations, property destruction, self-injurious behaviors, and aggression (Dartnall, Holmes, Morgan, & McDougle, 1999; Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996).

Treatment studies of adults with autism and mental retardation are rare (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Residential treatment programs developed specifically for adults with autism have emerged only recently and research on their effectiveness is limited (Van Bourgondien, Reichle, & Schopler, 2003). In one 2½ year study of eight men with autism and mild to severe retardation who were placed in a group home employing the Treatment and Education of Autistic and related Communication Handicapped Children model (TEACCH; Van Bourgondien &

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Reichle, 1997), Persson (2000) reported improvements in interpersonal behavior, leisure skills, vocational behavior and independent functioning. However of the 18 areas assessed, 12 showed no significant changes from the beginning to the end of the study. Also, one subject was excluded from the study for aggressive behavior. In one of the only studies with a control group, Van Bourgondien et al. (2003) found that providing a highly structured program based on the TEACCH model significantly improved the quality of treatment provided for six adolescents and adults with autism and mental retardation. While the participants' adaptive skills did not improve significantly over the course of the study, there was a significant reduction in behavior problems with the exception of stereotypies, which increased.

Autism in adults with severe to profound mental retardation presents one of the most significant clinical challenges facing practitioners in community-based settings. The severity and chronic nature of behavioral problems in this population combined with the consensus that no single approach is the best for all individuals with autism (Volkmar et al., 2004), suggests that additional strategies are needed to improve the overall quality of life for these individuals. As one adjunct to current treatment programs that emphasize contingency management training, Huynen, Lutzker, Bigelow, Touchette, and Campbell (1996) proposed planned activities training that focused on the antecedents rather than the consequences of behavior problems. This training program, which involved teaching maternal caregivers how to provide their children with structure, engaging activities, rules, and feedback, successfully increased the caregivers' skills and led to improvements in the children's behaviors. Similarly, Fox (2003) proposed an accommodation approach for adults with mental retardation and intractable behavior problems. Accommodation involves structuring an individual's environment to prevent or lessen the occurrence of challenging behaviors. More specifically, the primary focus of this accommodation approach was to identify precursors to problem behaviors and then through a structured routine of activities and staff approach behaviors, to alter these antecedents in order to reduce or eliminate their impact on the individual. In this vein,

Duker and Rasing (1989) altered the physical environment for three males with developmental disabilities and autistic-type behaviors (age range 16–26 years). By reducing the variety of visual stimulation available in the treatment setting, the researchers reported a decrease in self-stimulatory behavior and an increase in on-task behavior; other behavior problems such as aggression, self-injury, and disruptions were unchanged. Brown (1991) recommended that for adults with autism and mental retardation, in addition to behavioral strategies such as differential reinforcement of other behavior, a highly individualized daily schedule broken into 15 minute time increments should be designed to accommodate each person's unique characteristics and needs. One of the purposes of this structure was to have the individuals learn to recognize their routine by the sequence of predictable events that they experienced each day.

The purpose of the present study was to pilot an accommodation program for four adults with autism, severe to profound mental retardation and significant behavior problems. These individuals had a long history of treatment for their behavior problems including behavioral strategies and for three individuals, psychotropic medications. Despite these treatment efforts, staff members consistently reported that when external (e.g., room changes, new staff, disrupted routine) or internal changes occurred (e.g., medication change, illness, injury), these individuals often responded with a significant escalation in behavior problems including physical aggression, property destruction, self-stimulatory behaviors, increased general agitation, increased activity levels and self-abuse. To better accommodate these persons, a separate treatment environment including individualized daily activity schedules was created to meet each person's unique needs. In addition, potential environmental disruptions were minimized and procedures to more sensitively monitor internal changes were implemented.

Method

Setting and Participants

The setting for this study was a pre-vocational day training program for 75 adults with severe

to profound mental retardation, all of whom also were receiving residential care services. The day program was divided into 12 training rooms, each with five to eight individuals, two to three staff members, and an instructor who was responsible for supervising four training rooms. One of these existing training rooms was designated for the new accommodation program which eventually would include four individuals and two staff members. The selection criteria used to determine eligibility for the accommodation program included: (a) a diagnosis of severe to profound mental retardation based on the *Diagnostic and Statistical Manual of Mental Disorders* (DSM IV; American Psychological Association, 2000); (b) a DSM IV diagnosis of autism; and c) a history of significant challenging behaviors that were difficult for staff to manage and often interfered with peers in the other training rooms. Of the 14 individuals who met these criteria, four were selected based on discussions with staff. Direct care and supervisory staff members selected participants who were the most disruptive to the individuals in the other training rooms and the most challenging to manage.

Kurt, a 54 year-old male, was diagnosed with autistic disorder and severe mental retardation (IQ = 20). He had a long history of engaging in self-injurious behavior (SIB) that primarily involved him hitting and slapping his face. His SIB was very severe and had caused blindness in one eye, some damage to the other eye, and a number of bruises to the face and ears. While a combination of behavioral strategies and psychotropic medications implemented over several years had successfully reduced the frequency and severity of these episodes, the SIB continued to regularly occur. A functional behavioral assessment had determined that common triggers for Kurt's SIB were changes in routine (new staff member, another individual having a behavior problem) and personal changes (medication dosage change, ear infections).

Paul, a 31 year-old male, was diagnosed with autistic disorder and profound mental retardation (IQ = 13) with additional characteristics consistent with hyperactivity and obsessive compulsive disorder. Prior to the present study, Paul would frequently run out of his training room and attempt to exit the facility.

Paul also exhibited SIB, slapping himself repeatedly. A functional behavioral assessment indicated that these behaviors appeared to help Paul avoid or escape from anxiety-provoking situations such as loud noises and excessive commotion, staff intruding in his self-defined space, and spending too much time in one confined setting.

Bill, a 34 year-old male with Down's syndrome, was diagnosed with autistic disorder and profound mental retardation (IQ = 10), with a significant hearing loss in one ear. Bill had a history of aggressive behaviors including hitting, kicking, and shoving others. He also destroyed property and threw objects. Observations conducted within a functional analysis framework indicated that these behaviors occurred when Bill did not want to follow a staff member's request, when his demands were not met immediately, or in response to another individual's aggressive behavior.

Chris, a 43 year-old male, was diagnosed with autistic disorder and profound mental retardation (IQ = 11) with additional characteristics consistent with obsessive compulsive disorder and pica. Previous treatment programs had successfully addressed a number of behavioral issues including smearing and ingesting feces and property destruction. An ongoing behavioral issue was Chris' agitated body rocking and twirling. He would sit on the floor in a crouched posture and rock back and forth or stand and spin in circles for extended periods of time. A functional analysis suggested that these behaviors were largely self-stimulatory in nature and also served to help Chris avoid participating in training activities. The frequency and long duration of these episodes clearly interfered with Chris' ability to benefit from the training offered at the pre-vocational setting.

Participants starting time in the accommodation program was staggered to lessen the potential disruption in the new program and allow sufficient time for the staff to meet each individual's needs. Kurt and Paul began the program at the same time, followed three months later by Bill, and 10 months later by Chris.

Accommodation Program

The overall goal in the design of the accommodation program was to create a highly pre-

dictable environment, tailored to the unique characteristics and preferences of each individual, in order to strengthen adaptive and pre-vocational skills and to prevent the onset of challenging behaviors. The training room was arranged to respect each individual's space and preferences. For example, one individual preferred to work in a cushioned rocking chair at a table located away from others. Another individual preferred to sit close to the door so he could observe people going by as he worked on his tasks. Precursors to each individual's behavior problem were identified and eliminated or minimized as much as possible. For example, one participant became upset if another individual was having a behavior problem. His resulting accommodation procedure was to temporarily remove him from the training room until the other individual's behavior issue was resolved. One participant would become agitated if someone entered his personally defined space, made eye contact and spoke in a loud voice. As part of his accommodation program, staff always said his name before approaching him, and then spoke to him in a soft voice without making significant eye contact. Another individual would become aggressive if he saw foods or liquids. Consequently, these items were not kept in the training room and when they were brought in as reinforcers or snacks, he was offered his first. In addition to these accommodation procedures, daily tasks such as self-care skills, sorting, collating, shredding paper, and recycling cans were chosen to promote the development of their adaptive and prevocational skills. Preferred individual activities such as listening to music, looking at magazines, and rocking in a chair also were selected based on staff's historical knowledge of the individuals and the completion of a reinforcement survey for each participant (Fox & DeShaw, 1993). Also, each individual had a contingency management program that had been developed by an interdisciplinary team to strengthen prosocial behaviors and reduce challenging behaviors in both home and day training settings. Finally, the normal, ongoing activities at the prevocational setting such as snacks, lunch, and outings, were included and tailored to each individual's preferences (e.g., eating in a quiet setting, sitting in a favorite chair). All selected

tasks and activities were arranged within a highly structured daily routine, divided into 15 minute time segments that were rigorously adhered to. Posters displaying each individual's daily schedule were conveniently located for easy staff reference on the training room walls. The accommodation program was run year round, five days a week, from 8:30 a.m. to 2:30 p.m. Sample elements from each individual's accommodation program are provided below.

Kurt's accommodation program was designed to prevent SIB episodes. Staff felt this could be best accomplished by a predictable routine with tasks and activities that Kurt enjoyed. Following completion of pre-vocational tasks, Kurt was allowed to engage in a preferred activity such as bouncing a ball, sitting in a rocking chair, having a cup of coffee, or twirling a favorite towel. In addition, Kurt was given regular periods throughout the day when no demands were placed on him. An internal factor that contributed to Kurt's SIB was discomfort associated with wax build-up in his ears as well as ear infections. Consequently, a nurse checked his ears weekly and provided treatment (irrigation) when necessary.

Similar to Kurt, Paul's accommodation program was designed to prevent self-injury. Paul liked looking at magazines. Therefore, interspersed between prevocational tasks throughout the day, he was given the opportunity to look through a magazine. Paul also became quite anxious when he observed other individuals leaving the training room at the end of the day to return home. As a result, Paul's day was shortened and he was provided transportation home earlier than the others.

Bill's routine was designed to prevent the triggering of his aggressive behaviors. Like the other individuals, Bill's daily schedule was designed to provide him a predictable sequence of activities to strengthen and maintain his adaptive and pre-vocational skills. Throughout the day, when Bill completed each task in his daily routine such as washing hands, sorting items, and arts and crafts without resorting to pushing, hitting, kicking, or throwing items, he was rewarded with verbal praise and/or some form of sensory stimulation (battery-operated massager). As Bill had a history of fixating on battery-operated items and be-

coming aggressive when a staff member tried to retrieve one from him, Bill had access to only one such item and for a limited duration of time.

Chris, the individual with the agitated twirling and rocking behaviors, was given regular times interspersed throughout the day to spend engaging in sensory-stimulation activities such as holding a vibrating hand massager, listening to music, and sitting in a vestibular swing. He also had regular rewards for transitioning from one activity to another as these times had led to the spinning and rocking behaviors in the past.

Staff Training

The accommodation training room was staffed by two staff members with an instructor who supervised the classroom on an intermittent basis. The staff members were selected from the staff at the pre-vocational setting based on their proven ability to manage clients with challenging behaviors and a consistent attendance record. These staff members received specialized training that began with an overview of autism and its implications for working with these individuals. The rationale and procedures for the accommodation program were then reviewed. Next, each participant in the accommodation program, his daily schedule of tasks and activities, and details regarding how to best approach each individual to prevent and manage challenging behaviors were described in detail. The next training phase involved staff members learning to follow each individual's daily routine. This was accomplished through simulated exercises with a supervisory staff member role playing each participant in the accommodation program. As mentioned previously, posters were developed that showed the time and activity for each individual for the entire day. In addition, each individual had a daily data sheet that staff used to document task completion and program delivery as well as to record any challenging behaviors that occurred. These data sheets were also used to monitor the individuals' progress in the program and to make refinements in their daily schedules. For the next phase of training, staff members implemented the daily schedule with one individual while being shadowed by an instructor.

Once the staff member was comfortable implementing the daily program with one individual, other individuals were added until each staff member was familiar with the programs for all four individuals. In the final phase of training, the staff members independently implemented the accommodation program. During this phase, they were monitored several random times each week and provided feedback by the instructor for their consistency in following the individuals' daily schedules and for the accuracy and completeness of their data recording. In addition to ongoing staff meetings to discuss program implementation issues that arose, a monthly meeting was held with the consulting psychologist to assess program effectiveness and make any needed changes in the individuals' accommodation programs.

Behavioral Measures

The following specific challenging behaviors for each individual were identified to assess the effectiveness of the program: Kurt and Paul – episodes of SIB, each which often included several individual behavior incidents varying in severity; Bill – incidents of aggression including pushing, hitting, kicking, and throwing objects at others; and Chris – episodes of agitated rocking and body twirling which varied from less than a minute to several minutes in length. Prior research has demonstrated that training procedures and feedback increased the reliability of problem behavior recording in residential treatment facilities (Mazingo, Smith, Riordan, Reiss, & Bailey, 2006). Therefore, all of the individuals' behaviors were clearly defined for the staff members and a portion of the staff training included learning and demonstrating accurate behavior recording. The daily data sheets were used to record these behaviors. The baseline data was collected in each individual's original training room prior to entry into the accommodation treatment program. The same data was collected for each individual during their entire participation in the accommodation treatment program.

Results

The baseline period varied between 4 and 14 months depending on the individual's start-

TABLE 1

The average number of behavioral episodes for each individual for the baseline period and each year of participation in the accommodation treatment program.

Person	Challenging Behavior	Baseline Period		Treatment Program Years						
		Months	Mean	1	2	3	4	5	6	7
Kurt	Self-Injury	4	28.0	23.6	27.8	28.6	3.4	8.9	0.0	0.0
Paul	Self-Injury	4	8.5	8.3	3.0	0.8	0.4	0.2	0.1	0.0
Bill	Aggression	7	2.0	3.5	1.8	3.0	1.6	1.1	0.0	0.0
Chris	Rocking	14	6.9	9.3	3.8	2.6	0.8	2.8	0.2	0.0

ing date in the accommodation treatment program. The treatment program and data collection continued for seven years. Baseline and treatment data for each individual's behavioral measure is shown in Table 1. We also computed a treatment effect size by comparing each individual's average baseline data with the average data obtained each year for the entire treatment period. The effect sizes were computed using the mean baseline reduction formula (Campbell, 2004), which is calculated by subtracting the mean behavioral episodes during each treatment year from the mean episodes during baseline and then dividing by the mean baseline episodes and multiplying by 100. There was a consensus among staff members that the criterion to establish a significant treatment effect should be set at an 80% reduction in the targeted behavior problem for each individual.

As shown in Table 1, Kurt's SIB episodes remained frequent for the first three years he was involved in the accommodation program with monthly SIB episodes ranging from four to 58. At times, there were a number of factors that clearly contributed to Kurt's increased agitation and related SIB including an ongoing adjustment to the new program, regular ear infections, medication changes, introduction of new staff members, entry of other individuals in the program, and change in schedule due to weather, among others. At others times, no contributing factors could be identified. Staff also reported that the nature of Kurt's SIB was changing over time. He often entered the training room and would have an immediate SIB episode and then have no more incidents for the remainder of the day. Moreover, following the first few years in the

program, the staff considered the intensity of his SIB episodes as mild with no new injuries resulting from the SIB. Kurt met the 80% treatment effect size in his fourth year in the treatment program (effect size = 87.9 %). However, during the fifth year of treatment, his effect size reduced to 68.2%. For the final two years of treatment, Kurt achieved a 100% effect size. As shown in Table 1, Paul's SIB showed minimal change during the first year of the program. During this initial adjustment period, he ranged from one to 19 SIB episodes per month. However, by the second year, his SIB reduced by 64.7% and he met the 80% criteria during his third year in the program. While occasional episodes continued to occur over the next three years, the frequency of SIB episodes reduced each year. By the seventh year in the program, Paul achieved a 100% reduction in his SIB. Bill responded to the accommodation program with an initial increase in aggressive behaviors. During baseline, his monthly incidents ranged from 0–5 but increased to 15 in his third month in the accommodation program. During the subsequent months, his incidents again decreased in frequency and severity. At the beginning of the third year of treatment, Bill had become increasingly agitated and difficult to manage. After a medical examination, staff found that Bill had a fractured bone which clearly contributed to his increased agitation and aggression. Over the next two years, the frequency of his aggression gradually decreased and staff consistently reported that his aggression was less intense and more easily managed when it did occur. Bill did not achieve the 80% treatment effect criterion until his sixth year in the program where he obtained a 100% reduction

in his episodes that also were maintained in the final year of the program. Like Bill, Chris initially responded to the accommodation program with an increase in his agitated rocking behaviors that staff reported as very difficult to redirect. After the first year in the program, his behaviors improved. Staff attributed the change to the incorporation of the vestibular swing to Chris' daily routine. Chris met the 80% treatment effect size in his fourth year in the treatment program (effect size = 87.9 %). However, during the fifth year of treatment, his effect size reduced to 59.4%. By year six, his effect size increased 97.1% and he finally achieved a 100% reduction in his agitated rocking in the seventh year in the program.

Discussion

The four individuals in this study were grouped in the same treatment setting to reduce disruptions to their daily routine. This approach of creating a separate treatment environment was consistent with other comprehensive treatment programs for adults with autism and mental retardation (Persson, 2000; Van Bourgondien et al., 2003). Using a pre-established criterion-based treatment effect size to assess the participants' progress in the accommodation program, all participants met the 80% problem behavior reduction criterion in three to six years. Moreover, all participants achieved a treatment effect size of 100% by the final year of the program. Participant age and severity of behavior appeared to contribute to the need for a prolonged treatment period. For example, Kurt was 54 and had a long history of very significant self-injury. A consistent, predictable and sustained treatment environment over a four year period was required to impact his chronic and resistant behaviors. Ongoing disruptions to the individuals' lives also prolonged treatment. While every reasonable effort was made to reduce disruptions to the individuals' daily routines, this was not always possible. An initial period of adjustment to the new treatment setting and procedures, staff member absences and vacations, participants' illnesses and injuries, and medical and dental appointments were just a few of the myriad of possible factors that could have contributed to the in-

dividuals' agitation and related behavior problems.

While the present study focused on behavior problems, other benefits accrued from the accommodation program. With improved behavior, individuals were now consistently meeting their goals for the prevocational training programs that were implemented as part of their daily routines. Also, we were able to introduce new training programs such as recycling aluminum cans and shredding paper within the daily routines. Direct care staff members also were motivated to participate in the program. These staff received special training and support through regular meetings to review the participants' progress in the program. Their input regarding how to improve the program was valued and over time, the staff assumed more ownership for the success of the accommodation program. The staff turnover rate for the accommodation program was lower than the rates for staff in the other training rooms. In fact the two primary treatment staff stayed with the program for most of its duration. In addition to high staff satisfaction in working in this training setting, they also consistently reported that the accommodation program was having a positive impact on the quality of life for the individuals who participated (e.g., improved affect, greater level of participation in activities, reduced severity of behavior problems).

There also were limitations in this pilot program. While Paul's behaviors showed a steady decline over each year in the program, the other three individuals each experienced a one year relapse where behavior episodes increased after significant reductions had occurred the previous year. While all individuals eventually achieved 100% behavioral reduction levels by the final year of the program, it is reasonable to conclude that in the absence of the accommodation program, their behavior problems would reoccur and perhaps over time could increase to baseline levels. In agreement with Van Bourgondien et al. (2003), it makes sense to consider the accommodation program as a prosthetic device that "helps individuals with autism compensate for their deficits (similar to glasses or hearing aides)" (p. 139). As such, it may be necessary to continue this program indefinitely at least

for some individuals in order to maintain the highest quality of life possible for them.

The program evaluation format that was used to assess the impact of the accommodation program also had inherent limitations. For example, inter-rater reliability data was not collected on the behavioral measures. However, given that the behavior measures addressed clearly defined behavior problems that usually required staff intervention, we have confidence that our data were accurate. We also did not include a return to baseline condition or a control group. Both of these desirable research design features were not considered appropriate for this community-based treatment program. Also, given the severity of the behaviors we were treating, a return to baseline condition did not seem clinically prudent. Future studies that assess this accommodation treatment should consider using a multiple baseline design across individuals or settings to establish better research control. The latter design also would help determine whether the positive effects of this program generalized to other settings that the individuals experience (e.g., residence). Anecdotal evidence suggested that this generalization across settings did occur for our participants. Future research also needs to expand the outcome measures used to include changes in adaptive and other prosocial behaviors, prevocational skills, and staff and guardian satisfaction measures, to name a few. For now, the present study provides beginning evidence that accommodation is a promising adjunctive treatment to traditional contingency management and psychotropic medication treatments. In addition, this program can be implemented by direct care staff in community-based agencies and have a positive impact on adults with autism and mental retardation.

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