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**Medication Side Effects and Problem Behavior: A Context-based Approach to  
Assessment and Intervention in Home and Community Settings**

A Dissertation Presented

by

**Jamie Bleiweiss**

to

The Graduate School

in Partial Fulfillment of the

Requirements

for the Degree of

**Doctor of Philosophy**

in

**Clinical Psychology**

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Abstract of the Dissertation

**Medication Side Effects and Problem Behavior: A Context-based Approach to  
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Problem behavior significantly impedes multiple aspects of quality of life for individuals with developmental disabilities, and thus represents a major priority for intervention. Psychotropic medications are commonly administered to treat such behavior; however, these agents are often associated with adverse side effects that may have a negative impact on daily activities. The present study explored the possibility that commonly occurring medication side effects may function as setting events, a class of contextual variables that alter ongoing stimulus-response relationships (Kantor, 1959). That is, the presence of side effects purportedly made certain home and community routines more difficult for individuals, and this, in turn, produced greater levels of problem behavior. We demonstrated, experimentally, that the medication side effects did negatively affect particular family-based activities, resulting in an exacerbation of problem behavior. Additionally, the present study examined whether interventions aimed at mitigating these problematic routines and teaching skills to effectively cope with these contexts would result in a reduction of problem behavior and an overall improvement in quality of life. Nine children with developmental disabilities who were prescribed psychotropic medication to treat severe problem behavior participated. A comprehension assessment was conducted to identify problematic contexts in which side effects were present, and intervention packages were then developed and implemented collaboratively with each family. A multiple baseline experimental design was used to demonstrate intervention effects for these high priority contexts. Following intervention, significant improvements were noted in problem behavior, activity completion, and overall family quality of life. We discuss the value of conceptualizing medication side effects as setting events and the direct intervention implications arising from such a conceptualization.

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## Introduction

Children with autism typically demonstrate an array of deficits in communication skills and social behaviors. As a result of these impairments in the core domains, individuals with developmental disabilities often display a variety of problem behavior such as aggression, self-injury, and tantrums. Studies examining the prevalence of these behaviors have indicated rates that vary from 10% to 89% of the population engaging in at least one type of problem behavior, and individuals with more significant impairments have been found to exhibit more frequent and intense behaviors (Cooper et al., 2009; Emerson et al., 2001; Lowe et al., 2007; Qureshi & Alborz, 1992). Problem behavior has been found to significantly impact multiple aspects of family quality of life, and thus, represents a major priority for intervention (Lucyshyn, Dunlap, & Albin, 2002). For example, studies have found that severe problem behavior may prevent the successful integration of children into neighborhood schools (Koegel, Koegel, & Dunlap, 1996) and into the local community, and such behavior remains a leading cause of institutionalization and re-institutionalization of individuals with developmental disabilities (Lakin, Hill, Hauber, Bruininks, & Hill, 1983). The negative effect of problematic behavior on those living and working with the individual is evidenced by high rates of caregiver burnout and increased levels of caregiver distress (Koegel et al., 1992; Lucyshyn, Dunlap, & Albin, 2002). Additionally, these disruptive behaviors have been shown to be a major barrier to success in the workplace for individuals later in life (Bruininks, Hill, & Morreau, 1988). Given the negative impact that problem behavior can have on the individual displaying them, as well as on his/her caregivers, a great deal of

research and clinical work in both the behavioral and pharmacological fields has been dedicated to the development and implementation of effective interventions.

The behavioral literature is replete with studies demonstrating the importance of conducting a functional assessment to identify the antecedents and consequences that reliably evoke and maintain problem behavior in order to develop interventions that reduce such behavior (Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991; Horner, Carr, Strain, Todd, & Reed, 2002; Sprague & Horner, 1995). Importantly, research has documented that interventions based on a functional assessment are twice as likely to succeed as those that are not derived from a comprehensive assessment (Carr et al., 1999; Didden, Duker, & Korzilius, 1997; Scotti, Ujcich, Weigle, Holland, & Kirk, 1996). Thus, linking assessment information with intervention has emerged as a best practice in the field.

The linkage between assessment and intervention has been facilitated by the use of a conceptual model of problem behavior known as the four-term contingency, first proposed by Skinner (1938) and Kantor (1959). This model, delineating how contextual factors (setting events and discriminative stimuli) and reinforcing consequences interact to produce behavior, led to the emergence of a functional approach to the assessment of problem behavior in the field of applied behavior analysis (Bijou & Baer, 1961; Michael, 1982). Traditionally, research examining problem behavior focused largely on the identification of the consequences (functions) of behavior, and a substantial literature has amassed demonstrating that problem behavior can be maintained by escape from aversive task demands (Carr, Newsom, & Binkoff, 1980), escape from social interaction (Taylor & Carr, 1992), attention from others (Durand, Crimmins, Caulfield, & Taylor, 1989),

obtaining access to preferred tangible items (Durand & Crimmins, 1988), escape from aversive sensory stimuli (O'Reilly, 1997), and positive sensory reinforcement generated by the behavior itself (Favell, McGimsey, & Schell, 1982).

In recent years, however, the focus of research in the field has shifted, as investigators have increasingly begun to explore the pivotal role that context plays in producing problem behavior (Luiselli & Cameron, 1998; McGill, 1999; Smith & Iwata, 1997). Carr and Smith (1995) delineated a *contextual* model of problem behavior (shown in Figure 1) that essentially conceptualizes problem behavior as a function of two contextual variables: *discriminative stimuli* and *setting events*. A discriminative stimulus is a discrete event that immediately precedes the behavior, and in whose presence a response is reliably reinforced (Skinner, 1939). The presence of a given discriminative stimulus predicts that reinforcement will occur, contingent upon the performance of the response (i.e., the behavior). Thus, in the future, whenever the discriminative stimulus is present, the response is more likely to be displayed. The other contextual factor, the setting event, is a variable that influences the ongoing relationship between the discriminative stimulus and the response (Bijou & Baer, 1961; Kantor, 1959).

To illustrate the four-term contingency, as depicted in Figure 1, and thus, to demonstrate the relationship between contextual factors and reinforcing consequences in producing problem behavior, consider the following example of a young girl with a developmental disability who occasionally exhibits problem behavior (e.g., aggression) when her parents ask her to take a shower. On some days (Figure 1, line A), her parents ask her to take a shower (discriminative stimulus) and she complies (response); her parents subsequently provide her with praise when she complies with the request

(consequence). However, on other days (Figure 1, line B), her parents present her with the same request to take a shower (discriminative stimulus), and she displays severe aggression (response). Her parents respond to her aggressive behavior ultimately by removing the demand to take the shower (consequence). Additional assessment and observation may reveal that on the days she demonstrates aggression, the girl is experiencing elevated levels of fatigue. In this example, fatigue functions as a setting event, increasing the aversiveness of the task demand (discriminative stimulus), and consequently, the reinforcement value of escaping from the task of showering. Essentially, on days in which she is fatigued (setting event) and asked to take a shower (discriminative stimulus), she is more likely to display aggression. On days in which she is not fatigued, the discriminative stimulus is not as aversive, and the girl is more likely to comply with the request. The setting event (fatigue) in this example is thought to function as an “establishing operation (Michael, 1982),” as it is a variable that increases the aversiveness of the demand, thus strengthening any behavior (e.g., aggression) that reliably allows the child to avoid or escape having to comply with the demand. In essence, the aggression is negatively reinforced to a greater degree when the setting event (e.g., fatigue) is present than when it is not. Thus, over time, this escape-motivated aggression becomes more and more closely associated with a *particular context* (i.e., fatigue plus brushing teeth demands). As demonstrated in this example, it becomes apparent how “problem contexts” may be created through the influence of a four-term contingency. Accordingly, an emerging literature has begun to focus on the premise that *problem contexts produce problem behavior; thus, by adjusting the focus of assessment*

*and intervention efforts to problem contexts, we should be able to reduce or eliminate problem behavior.*

A review of the behavioral literature shows that there are three broad categories of setting events commonly associated with problem behavior: social, activities/routines, and biological. First, the variables involved may be social in nature, including factors relating to the presence or absence of specific individuals in the environment (Touchette, MacDonald & Langer, 1985), or low levels of attention from others (Taylor, Sission, McKelvey, & Trefelner, 1993). Second, the factors may be related to some aspect of ongoing activities or routines, such as transitioning from one setting to another (McCord, Thomson, & Iwata, 2001; Doss & Reichle, 1991; Davis, 1987). Third, the factors may be biological in nature, including fatigue and physical discomfort (Wiggs & Stores, 1996; Carr, Smith, Giacini, Whelan & Pancari, 2003; O'Reilly, 1997). For example, Carr et al., (2003) demonstrated an association between menstrual discomfort (a biological setting event) and increased levels of problem behavior displayed by participants. During periods of menstrual pain, participants were shown to display higher rates of problem behavior in response to task demands (discriminative stimuli). Following the implementation of a multicomponent intervention package that involved the use of over-the-counter medication that altered the context (i.e., alleviated menstrual discomfort), as well as the use of psychosocial interventions to address difficult task demands, subsequent reductions in problem behavior were noted.

Given the increased awareness of how these various contextual factors interact with consequences to produce problem behavior, a greater number of studies have begun to focus on the assessment and intervention of context variables (Clarke, Dunlap, &

Vaughn, 1999; Vaughn, Dunlap, Fox, Clarke, & Bucy, 1997). For example, Vaughn, Clarke, and Dunlap (1997) demonstrated the efficacy of implementing a context-based intervention to reduce severe problem behavior displayed by an 8-year-old boy during two family routines: using the bathroom in the home, and dining in a restaurant.

Assessment data indicated that the child displayed problem behavior including aggression and property destruction when required to transition to a less-preferred activity (i.e., using the bathroom), and when having to wait during the restaurant routine. Multi-component interventions implemented in the family routines involved the use of a visual schedule of the activity sequence that included a picture of a preferred item that was delivered upon successful completion of the toileting routine, and for the restaurant routine, the intervention included increasing the child's participation in the various tasks involved in the routine (e.g., ordering, paying for food). Substantial reductions in disruptive behavior and corresponding increases in engagement resulted from the implementation of the assessment-based, contextually appropriate interventions.

#### *Pharmacological Intervention*

The other major approach to intervention used to reduce or eliminate problem behavior is pharmacological in nature. There is an emerging literature examining the use of an array of different classes of psychotropic medications to reduce or eliminate problem behavior displayed by individuals with autism (Hellings, et al., 2005; Hollander, Dolgoff-Kaspar, Cartwright, Rawitt, & Novotny, 2001; Kolevzon, Matthewson, & Hollander, 2006; Posey, Puntney, Sasher, Kem, & McDougle, 2004; RUPP, 2002; RUPP, 2005; Shea et al., 2004). Psychotropic medications include any agent that is prescribed to stabilize or improve mood, mental status, or behavior (Julien, 2003). Common examples

of the various classes of psychotropic drugs include antipsychotics (e.g., risperidone, aripiprazole), antidepressants (e.g., fluoxetine, paroxetine), anxiolytics (e.g., lorazepam, diazepam), stimulants (e.g., methylphenidate), and mood stabilizers (e.g., carbamazepine, oxcarbamazepine). Studies have revealed that the use of these medications to treat both children and adults with autism has steadily increased over the past decade, with the atypical antipsychotic agents representing the class of medication that has evidenced the most significant increase in rate of prescription (Lott et al., 2004; Mandell, Morales, Marcus, Stahmer, Doshi, & Polsky, 2008; Patel et al, 2005; Vitiello, Zuveka, & Norquist, 2006). In a recent study examining national estimates of psychotropic drug use among Medicaid enrolled children and adolescents with autism, Mandell and colleagues (2008) reported that 56% of participants in their sample were prescribed at least one medication, and 20% were administered three or more medications concurrently. Results from this large-scale study highlight the increasing trend in the prescribing practices and the use of polypharmacy with this population, that is, the administration of more than one medication at the same time.

A number of open-label and placebo-controlled studies have been conducted, examining the efficacy of different classes of psychotropic medications, many of which have documented the benefits of these agents in reducing serious types of problem behavior in this population (McDougle, Stigler, & Posey, 2003; Namerow, Prakash, Bostic, Prince, Monutreaux, 2003; Parikh, Kolevzon, & Hollander, 2008; RUPP, 2005; Staller, 2003). For example, the Research Units on Pediatric Psychopharmacology Autism Network conducted a multisite, randomized, double-blind study investigating the efficacy of risperidone as compared with placebo for treatment of aggression, tantrums,



and self-injurious behavior in children with autism. Children treated with risperidone evidenced a statistically significant reduction of scores on the Aberrant Behavior Checklist-Irritability subscale, as compared with individuals in the placebo group. Additionally, investigators found a higher rate of positive response for those in the risperidone group, as demonstrated by ratings of *much improved* or *very much improved* on the Clinical Global Impressions Scale (RUPP, 2002). Although risperidone was the first drug approved by the U.S. Food and Drug Administration (FDA) to treat irritability and related behaviors associated with autism (FDA, 2006), a recent study, conducted by Tyrer and colleagues (2008) examining the efficacy of risperidone, haloperidol, and placebo on aggressive behavior, found that patients receiving placebo treatment demonstrated the most significant reductions in problem behavior, as compared to individuals who were prescribed either of the two antipsychotic medications.

Despite the benefits of various psychotropic medications that have been documented in this emerging literature, it is important to note that these drugs are often associated with adverse side effects (PDR, 2004), which are broadly defined as any drug-induced effect accompanying the primary effect for which the drug is administered. Although a wide array of symptoms have been identified as side effects in both the research and in clinical practice, the majority of studies investigating medication side effects have tended to focus primarily on the more severe and permanent adverse events including tardive dyskinesia, motor tics, and tremors (Malone, Maislin, Choudhury, Gifford, & Delaney, 2002; Nicolson, Awad, & Sloman, 1998; Hardan, Johnson, Johnson, & Hrecznyj, 1996). Thus, there is a need for empirical studies that examine other more commonly experienced side effects such as fatigue, increased appetite (hunger),

gastrointestinal pain or discomfort, as many of these same symptoms have been noted in the behavioral literature, where they are referred to as setting events. As described previously, these contextual factors have been found to be associated with increased levels of problem behavior. Thus, it is plausible that medication side effects actually function as biological setting events. For instance, Bosch, Van Dyke, Milligan Smith and Poulton (1997) reported that individuals experiencing abdominal pain resulting from a medical condition (gastrointestinal disturbances including ulceration and inflammation of the digestive tract, and severe constipation) displayed higher rates of self-injury, aggression, and disruptive behavior. Significantly, gastrointestinal disturbances producing pain and discomfort (e.g., abdominal pain, nausea, and constipation) have also been documented as commonly occurring side effects of various medications (PDR, 2004). Conceivably, these side effects, as well as numerous others noted in the literature, could operate in the same manner as non-drug induced pain and discomfort, making specific activities and routines more aversive than they would typically be, thereby increasing the likelihood that problem behavior will be displayed. Therefore, it may be the case that drug side effects, paradoxically exacerbate problem behavior by functioning as setting events in specific contexts. That is, when these symptoms are present, they negatively impact certain activities and routines and consequently increase the likelihood that problem behavior will be displayed by the individual.

To illustrate this proposed paradox, recall the previous example describing a girl who displayed problem behavior on days when she experienced fatigue. Consider the possibility that due to the severity of her problem behavior, the girl is prescribed a psychotropic medication. Consequently, the drug is accompanied by several side effects

including increased levels of fatigue. This symptom presumably functions in a manner similar to fatigue caused by a lack of sleep (described previously as a biological setting event), and accordingly makes certain tasks (e.g., take a shower) more aversive than usual, ultimately resulting in an exacerbation of problem behavior (i.e., the target of the medication). Therefore, escape from the task, via aggression, becomes more reinforcing for the child, thus, in the future, the combination of drug-induced fatigue and task demands is more likely to set off aggressive behavior (Figure 1, Line C). Paradoxically, the drug given for problem behavior sets in motion a process that culminates in additional problem behavior. This outcome argues for a closer examination of how individuals respond to the particular drugs they are receiving.

The aim of the current study was two-fold; first, we intended to experimentally demonstrate that there was an association between medication side effects, compromised performance in common home and community routines, and elevated levels of problem behavior. Essentially, we proposed to examine the possibility that medication side effects were in fact functioning as setting events in certain activities, resulting in an exacerbation of the problem behavior the drug was originally prescribed to treat.

A second goal of the study was to develop and subsequently implement empirically validated behavioral interventions in the problematic activities in which side effects were present, in order to reduce or eliminate the problem behavior, and in turn, enhance the overall effectiveness of the medication. While the intervention strategies implemented were tailored to the specific contexts of each participant, a generic model of intervention was employed that consisted of mitigation and coping strategies. These strategies have a common element, namely, that they both involve the introduction of

stimuli that evoke nonproblem behavior that, in turn, compete with those stimuli inherent in the problem context that generates problem behavior.

In illustration, mitigation strategies can include introducing stimuli for nonproblem behavior using strategies involving (but not limited to): visual activity schedules, neutralizing routines, embedding, and visual representations of time (i.e., using a timer). The use of visual activity schedules involves visually representing the activities that will occur throughout the day, or depicting the specific sequence of steps involved in a particular task or routine, using pictures or written words. These schedules are reviewed with the individual and kept within view throughout the activity to make it more predictable and easier to complete. Studies have shown that this added predictability is associated with reductions in problem behavior displayed by individuals (Schmit, Alper, Raschke, & Ryndak, 2000). Neutralizing routines involve providing the individual the opportunity to engage in a preferred activity after experiencing a negative setting event and prior to being presented with a difficult demand. For example, if an individual is hungry (causing discomfort), he may be provided with a snack to reduce the hunger prior to being presented with a demand to complete a difficult task (e.g., homework). This procedure has been shown to effectively reduce problem behavior (Horner, Day, & Day, 1997). Embedding is a strategy that involves providing an individual with access to preferred activities intermixed with disliked activities, and has been found to be associated with significant decreases in problem behavior displayed by individuals with developmental disabilities (Blair, Umbreit, & Bos, 1999). The use of a visual representation of time (i.e., a timer) has been found to enhance predictability and,

consequently, reduce problem behavior in individuals with developmental disabilities (Dettmer, Simpson, Myles, & Ganz, 2000).

In the case of mitigation, it is the *adult* (e.g., parent, teacher) who acquires skills that result in the introduction of stimuli for nonproblem behavior that compete with the stimuli associated with problem behavior in a given context. However, in the case of coping skill strategies, it is the *child* who acquires the skills that eventually result in the introduction of stimuli for nonproblem behavior in a given context. For example, an individual could cope with a problem context by being taught (acquiring) new skills involving (but not limited to): functional communication (Carr & Durand, 1985), relaxation (Mullins & Christian, 2001), and choice making (Bambara, Koger, Katzer, & Davenport, 1995). Each of these more adaptive (appropriate) skills can impact the problem context by eventually generating stimuli for nonproblem behavior. In illustration, a child who communicates “it’s too noisy and crowded” in response to a loud and crowded setting may influence his/her parent to alter the problem context (e.g., lowering the level of noise he/she is exposed to, or taking the child to a quieter location, thus providing new stimuli that can evoke appropriate, nonproblem behavior). Coping strategies have been found to be effective in not only reducing problem behavior, but also in engendering a sense of empowerment and increased control over one’s environment, which are meaningful outcomes often overlooked in the treatment of individuals with developmental disabilities (Wehmeyer, Kelchner, & Richards, 1996). At a conceptual level, every mitigation and coping strategy has one common underlying element: The procedure essentially introduces into the problem context, directly or indirectly, stimuli that evoke nonproblem behavior.

It is important to note that the investigators had no direct involvement with the medication administration. Rather, families who participated in the study were already under the care of a physician who had previously prescribed medication for the children, as part of their ongoing clinical treatment. Parents of individuals who were *already* taking medication for problem behavior were asked a variety of questions regarding their child's medication history, daily functioning, whether their child experiences any side effects, as well as questions about their child's problem behavior. Direct observations were conducted to confirm the presence of medication side effects and problem behavior in identified problematic contexts, and intervention packages were created to teach the family a variety of behavioral techniques to help mitigate the difficult routines and to teach the child more effective ways of coping with the side effects to ultimately reduce the problem behavior and in turn, enhance family quality of life.

### *Overview*

Three distinct studies were conducted to investigate and subsequently remediate three broad categories of problematic home and community contexts (i.e., routines in which medication side effects were present and potentially functioning as setting events) associated with problem behavior. The focus of the first study was on home-based routines involving task-demands; the second, on community-based activities; and the third study focused on contexts associated with transitioning between settings or activities. For each general category of contexts, one priority context was identified for each of the three participants. Within the home routines category, the specific priority contexts identified were: (1) mealtime routine, (2) homework routine, and (3) daily household chores. Within the community-based activities category, the priority contexts

specified were: (1) eating a meal in a restaurant, (2) going to the supermarket, and (3) going to the doctor. Within the transitioning between settings or activities category, the priority contexts identified included: (1) transitioning to and from the car, (2) the morning transition to school, and (3) transitioning between locations during community outings.

Each study involved seven components. First, participants were selected based on predetermined inclusion criteria and the results of the Structured Interview for Assessment of Medication Side Effects (SIAMSE; Carr & Bleiweiss, in preparation for publication; Appendix A) completed by parents (discussed shortly). Each family generated a list of activities that had become more difficult to successfully complete since the child went on the specified medication regimen (presumably due to the presence of medication side effects), and they then identified a priority context (i.e., the experimental context) which became the focus of the intervention in subsequent phases. Detailed information about the child's medication regimen, the problematic contexts, and the nature of problem behavior was gathered, and global measures assessing family functioning and quality of life were administered. Second, validation observations were conducted (i.e., the initial baseline sessions) to confirm the results obtained from the SIAMSE, as well as the presence of problem behavior in the identified priority context. After five validation sessions were conducted, the third component was initiated, which consisted of extended baseline sessions (involving direct observation and data collection) that were conducted to confirm the presence of problem behavior in the identified priority context. Fourth, an intervention package was developed, in collaboration with each family, based on the assessment information, and the intervention agents (i.e., the parents) were trained to implement the various intervention strategies. Importantly, while

there were numerous intervention options possible across the various contexts, and even for the same context, the options that were ultimately selected for each participant included those endorsed by parents, during a collaborative problem-solving process, in which parents identified the options that they deemed best suited to address the unique characteristics of their family situation. Fifth, the intervention package was implemented in the specified priority contexts. Intervention fidelity checks were completed to assess the integrity of intervention implementation, direct observations were conducted by multiple informants, and data were collected on behavioral outcomes. Sixth, interventions were developed and implemented in an additional two to four contexts (i.e., “clinical extension”) identified by families as being problematic and negatively impacting family quality of life. Formal data collection did not occur in these clinical extension contexts, due to the intrusive nature of the data collection process. While the priority (experimental) contexts reflected one of the three broad context categories previously described, the clinical extension contexts could be selected from any or all categories of contexts. The seventh and final component involved the post-intervention assessment of global measures of problem behavior, family functioning, and family quality of life.

## STUDY 1: HOME-BASED ROUTINES AS A CONTEXT FOR PROBLEM

### BEHAVIOR

#### Method

#### *Overview*

Three families participated in Study 1, and each identified a home-based routine as their respective priority context. Participants were identified by a local agency that served individuals with developmental disabilities, and were required to meet the



following inclusion criteria: (1) the child had a diagnosis of a developmental disability made by a psychiatrist, psychologist, and/or neurologist, (2) he/she was residing at home with their family, (3) the child was on one or more psychotropic medications, as prescribed by a physician, for a period of at least two weeks, to treat problem behavior, (4) parents reported that their child experienced difficulty in one or more home and/or community activities, and (5) the child had a history of engaging in problem behavior (e.g., self-injury, aggression, tantrums, property destruction) in these difficult activities as confirmed by clinically significant scores on the Aberrant Behavior Checklist-Community-Irritability subscale (ABC-Community, Aman & Singh, 1994). Exclusion criteria for the study included: (1) the primary parent's availability to collect data on an ongoing basis throughout the various phases of the study, and (2) the parent's agreement to have their child remain on their current medication regimen (i.e., no alterations in the dosage of the drug, additions or discontinuations of the medication administered to their child throughout the duration of the study to reduce potential confounding variables).

The Structured Interview for Assessment of Medication Side Effects (SIAMSE) was administered to parents in order to assess the nature of their child's medication regimen, including a thorough evaluation of the side effects that may have been experienced, as well as to obtain information about problematic contexts and problem behavior (Carr & Bleiweiss, in preparation for publication; Appendix A). The SIAMSE is a semi-structured, comprehensive interview that assesses medication side effects to determine whether an association exists between the presence of commonly occurring medication side effects in specific home and community routines and a subsequent exacerbation of problem behavior displayed in those contexts. It was used to obtain

information about the nature of the vast array of medication side effects experienced by participants, including the frequency, duration, and the level of intensity of the symptoms, using a 5-point Likert scale that ranged from 1 (*mild*) to 5 (*severe*).

Additionally, parents identified the particular home and community routines that they felt had become more difficult for their child to successfully complete since going on the current combination of medication, and they subsequently rated the impact (i.e., degree of difficulty) that the presence of the side effects had on the successful completion of these activities, using a 5-point Likert scale that ranged from 1 (*mild*) to 5 (*severe*). The final section of the SIAMSE involved an assessment of problem behavior displayed by the child in the contexts that were identified as being difficult to complete. Specifically, parents were asked to indicate whether their child exhibited problem behavior during the difficult routines when side effects were present, and if problem behavior was present, they were asked to rate the overall level of severity of the problem behavior, using a 5-point Likert scale that ranged from 1 (*mild*) to 5 (*severe*).

After completing the interview, parents were asked to identify the *one* activity (from the list of the various contexts nominated during the administration of the SIAMSE) that they felt had become the most problematic since their child had gone on their current medication combination (i.e., the context in which medication side effects were present at elevated levels of intensity, contributing to a greater level of difficulty experienced, and ultimately resulting in increased levels of problem behavior). This activity that constituted the parents' top priority and produced the greatest disruption for the family became the primary focus of the intervention, and was referred to as the *experimental context*. Direct observations were conducted by multiple informants and

data collection occurred in the experimental context throughout subsequent phases of the study.

Parents were given the opportunity to identify additional routines that had become more difficult for their child to successfully complete, presumably due to the presence of medication side effects, and that were associated elevated levels of problem behavior. These secondary problematic routines were referred to as the *clinical extension contexts*. While intervention packages were developed and implemented in these contexts to address problem behavior, no formal data collection occurred due to the intrusive nature of the data collection process.

Following the identification of the experimental context, parents were administered a series of additional measures to further assess the problem behavior exhibited by their child, as well as to evaluate overall family functioning and quality of life. Specifically, the assessment measures included: the Irritability subscale of the Aberrant Behavior Checklist-Community (ABC-I; Aman & Singh, 1994) that assessed the global perception of the level of severe problem behavior; the Home Situations Questionnaire (HSQ; Barkley, 1981) that was used to evaluate the extent to which the child's problem behavior disrupted commonly occurring home routines such as mealtime, bedtime, and grooming; the Residential Lifestyle Inventory (RLI; Kennedy, Horner, Newton & Kanda, 1990) that measured family involvement in various community activities such as visiting family or friends, and going to the movies. Additionally, parents completed measures that assessed their level of distress, as well as their perceptions of their role as a parent and their ability to care for a child diagnosed with developmental disabilities. The Parenting Stress Index-Short Form (PSI-SF; Abidin,

1997) was administered as a means of evaluating the amount of distress parents experienced in their daily lives, and the Developmental Disability Parent Depression/Stress Questionnaire (DDPD/SQ) was administered to supplement the standardized, global measures and to provide a further assessment of distress specifically associated with parenting a child with developmental disabilities.

A follow-up assessment was conducted for each family, based on information parents provided during the SIAMSE administration, utilizing the format outlined by O'Neill, Horner, Albin, Storey, and Sprague (1997; Appendix B). The purpose of this assessment was to provide a more detailed description of the specific circumstances and situations that evoked and maintained problem behavior in the experimental context. For example, if a family endorsed "homework" as the most problematic context, follow-up questions assessed the specific tasks involved in the activity (e.g., taking out homework material, completing difficult assignments, receiving feedback from parent), with whom the problem behavior was most likely to occur during the activity (e.g., mother), in what setting this activity was most likely to be associated with problem behavior (e.g., sitting at the kitchen table while younger brother also worked on homework), the time of day that this activity was most likely to be associated with problem behavior (e.g., shortly after getting home from school), the parental response to the problem behavior (e.g., demands to complete homework assignments withdrawn), and, finally, the child's reaction to the parental response (e.g., child escaped the demand and no longer displayed problem behavior). The follow-up questions produced detailed assessment information that was useful in the development of the multi-component intervention packages created for each family.

Baseline observations were conducted in the experimental (priority) context for each family, and baseline was divided into two components: an initial validation phase and an extended baseline phase. The initial validation phase, consisting of five sessions, served primarily to validate the results of the SIAMSE, and to confirm the presence of problem behavior in the identified experimental contexts. For each participant, multiple informants, namely, a primary parent rater, a second caregiver, the primary investigator, and a second researcher (who was blind to the research hypotheses of the study) conducted observations in the experimental context and assessed several variables including: the number of task steps completed in the identified routine, the latency to the onset of problem behavior, and the reason for session termination. In addition, parent raters collected data on ancillary variables which included ratings of the intensity level of the side effects that were present in their priority routines, the level of difficulty that was experienced while participating in the problematic contexts, as well as the level of severity of problem behavior. Following the completion of the five validation sessions, the extended baseline phase was initiated for each family. The same observation and data collection procedures were utilized throughout both the initial and extended baseline phases. After baseline observations had been completed, parents met with the first author to develop multicomponent, context-based interventions to reduce problem behavior.

In accord with best practice guidelines, parents were included in the development of the intervention packages created for their respective experimental contexts (e.g., Lucyshyn, Albin, & Nixon, 1997; Vaughn et al., 1997), as they were able to provide the most insight about what was feasible given their particular family situation. A problem-solving approach to intervention development was utilized (D’Zurilla & Nezu, 2001;

Stiebel, 1999). During a single session, family members and the primary investigator worked systematically through a problem-solving template (Appendix C) applied to each routine that was targeted for intervention. The final list of intervention strategies that were developed can be found in Appendix D. In illustration, during the problematic context of the “mealtime routine,” it was suggested that the child be provided with the opportunity to listen to music (a highly preferred activity) while setting the table (a less preferred activity often associated with problem behavior when certain side effects were present). The parents noted that their child often responded positively (i.e., she was more likely to display appropriate behavior) when given the opportunity to listen to music on her iPod. Further, the parents explained that this was a simple and unobtrusive strategy that could be easily implemented during the mealtime routine. Thus, we incorporated that discriminative stimulus for appropriate behavior (i.e., the iPod) into the problematic mealtime context. As this strategy represented a “good fit” to this typical family routine, it was included as part of the intervention package.

The intervention strategies that were developed in collaboration with parents involved both mitigation and coping procedures. Mitigation strategies included procedures in which *parents* were taught to introduce stimuli associated with appropriate (nonproblem) behavior into the problematic context. Coping strategies included procedures in which the *child* was taught to behave in a manner that resulted in the introduction of stimuli associated with appropriate behavior into the problematic context. Additionally, the intervention design included efforts to ascertain whether each recommended strategy was compatible with existing family values, ideals, and goals

(Albin, Lucyshyn, Horner, & Flannery, 1996), that is, the “goodness-of-fit” of the intervention.

Following the problem-solving session with the investigator, parents were trained to implement the various components of the intervention. Training was typically 1 to 2 sessions in duration. Decision rules regarding when training with the investigator was to be discontinued (i.e., intervention agents were able to independently implement the various strategies) are displayed in Appendix E.

A multiple baseline design across the three participants (Hersen & Barlow, 1976) was used to examine the impact of intervention strategies on problem behavior that occurred during problematic routines (i.e., experimental contexts in which medication side effects were present). After each family had successfully run three intervention sessions without the investigator providing assistance, an independent variable integrity check was conducted by the investigator. Once each family had successfully implemented all of the components of the intervention package in the experimental context, additional activities that parents had identified as becoming more problematic (due to the presence of side effects) and consequently were more likely to be associated with problem behavior were reviewed and selected as the clinical extension contexts. Problem-solving techniques (described previously) were utilized with each family to develop additional mitigation and coping strategies that were specifically tailored for these routines. Although families were trained to implement these strategies in the same manner as in the experimental context, no formal data collection occurred in these additional contexts. Previous research conducted with families had informed us that collecting detailed data in multiple contexts was highly disruptive to family life.

Importantly, interventions continued to be implemented in the experimental context while clinical extension contexts were identified and intervened upon. Once the intervention phase was completed, each family was re-administered the battery of assessment measures that had been completed in the initial phase of the study, as well as several ancillary global measures to assess the impact of intervention on problem behavior and on overall family quality of life.

### *Response Definitions*

A medication side effect was defined as any drug induced symptom that had accompanied the intended primary effect for which the drug was administered (Julien, 2003). For the current series of studies, general categories of commonly occurring side effects included physiological or biological symptoms (e.g., fatigue, increased appetite/weight gain, gastrointestinal symptoms), conditions or symptoms affecting the cognitive domain (e.g., difficulty paying attention, confusion, memory loss), symptoms that were affective in nature (e.g., irritability, mood swings, anxiety), or conditions that affected fine and gross motor functioning (e.g., tics, tremors, paroxysmal movements, lack of coordination). Side effects were typically considered problematic when they substantially impaired an individual's ability to function due to the rate of frequency of the symptoms, how long they lasted, and how intense these side effects were when present.

Problem behavior was defined as any of the following: (1) aggression (e.g., punching, hitting, kicking, biting, grabbing, or striking others or shoving another person with an object, or using inappropriate language, cursing that is intended to berate, intimidate, or offend another, etc.), (2) self-injurious behavior (e.g., biting, hitting,



punching oneself, or banging ones head against an object), (3) property destruction (e.g., throwing, striking, or destroying an object), (4) tantrum behavior (e.g., more than 5 seconds of screaming, accompanied by throwing oneself on the floor and flailing arms and legs), and (5) non-compliance (e.g., refusal to follow directions or to participate in or complete a task or activity, dropping to the floor and refusing to move, stand up or respond to prompts or directives, or refusal to respond to directives, either by not physically responding or by verbally refusing by stating “no”).

#### *Participant and Context Selection*

As noted previously, each family indicated that their child was more likely to display problem behavior during specific home-based routines when medication side effects were present, as these symptoms appeared to make the activities more difficult for the child to successfully complete. The priority (experimental) home-based contexts included: for Alexa, “the mealtime routine,” for Scott, “the homework routine,” and for Robby, “the household chores routine.”

#### *Participant 1: Alexa*

Alexa was a 15-year-old female diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (Full Scale IQ = 66, Stanford-Binet Scales of Intelligence, Fifth Edition), who attended a special education program in a private school, and resided at home with her mother, father, and maternal grandfather. She had well-developed verbal communication skills, and used complete, multi-word sentences to communicate.

*Medication and Side Effects Profile.* Alexa’s medication regimen throughout the course of the study included: methylphenidate hydrochloride (40 mg/day administered in

the morning); oxcarbazepine (600mg/day, administered in the morning and evening); and clonidine hydrochloride (0.1mg/day, administered in the evening). Alexa's parents noted that she had been on the current regimen, without any changes, for approximately 5 months prior to the start of the study.

Her parents reported that Alexa appeared to experience a variety of side effects from the medication combination she was on, including: increased levels of irritability and agitation, a marked increase in anxiety, more frequent headaches, and decreased appetite. According to her parents, Alexa appeared to be much more irritable and physically agitated (e.g., she was more restless and more frequently engaged in disruptive self-stimulatory behaviors), particularly later in the day and into the evening, and they stated that she more frequently displayed a negative affect, in that she would suddenly breakdown and cry or she would become excessively angry with seemingly little provocation. In addition, they reported that Alexa appeared to experience a heightened level of anxiety, noting that she was more easily startled and bothered by certain environmental stimuli (e.g., loud, unexpected noises, dog barking, vacuum), and that she more frequently engaged in compulsive-type behaviors (e.g., repetitively picking the skin on her fingers and scabs on her arms and legs). Further, they stated that since going on the most current combination of medication, Alexa complained of having headaches more frequently. Finally, her parents noted that Alexa's appetite had substantially decreased during the day, as she frequently stated that she was not hungry and she ate much smaller portions at mealtimes.

*Context Selection.* Alexa's mother and father participated in the initial assessment, and were both administered the SIAMSE. According to their responses, they indicated

that the “mealtime routine” was the most problematic activity for Alexa since starting the most current medication regimen (i.e., this routine was rated a 5 “much more difficult to complete,” on the 5-point Likert scale that measured the level of difficulty of home and community activities); thus, this routine was selected as the experimental context, and became the focus of the intervention. Specifically, her parents stated that when the medication side effects were present, namely, headaches, decreased appetite, and intense levels of irritability and agitation, they greatly interfered with Alexa’s ability to complete the mealtime routine, and ultimately resulted in an exacerbation of problem behavior that was displayed in this context.

During the follow-up assessment, Alexa’s parents noted that when she experienced increased levels of agitation and irritability, or when she had a headache, she became more easily frustrated when presented with simple requests or task demands. Additionally, they explained that when she experienced these symptoms, her tolerance for sensory input or stimulation was reduced, and she would often become overly distressed by minor annoyances or disruptions (e.g., dog barking, mother answering the phone nearby). Moreover, they reported that Alexa’s appetite had been reduced since going on the medication, and she often was not hungry during the usual time the family ate dinner. They stated that frequently when she was presented with requests to come to the table for dinner, and she was not hungry, she seemed to become increasingly frustrated and angry. Thus, her parents indicated that when these side effects were present, the mealtime routine became much more aversive and challenging for her to complete, and consequently, when Alexa experienced greater difficulty completing the mealtime routine, she was much more likely to display more severe levels of problem

behavior (e.g., verbal aggression, protesting, tantrum behavior, property destruction, and noncompliance) in this context, than had been the case prior to going on the current regimen.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional activities that had become more problematic since going on the current combination of medication, seemingly due to the presence of side effects. These routines were identified as the clinical extension contexts, and included: “grooming” and “homework routine.” Although data collection did not occur in these contexts, Alexa’s family was provided with additional mitigation and coping strategies to address difficulties encountered while completing these routines.

*Participant 2: Scott*

Scott was an 8-year-old boy diagnosed with Asperger’s Disorder (Full Scale IQ = 110, Wechsler Intelligence Scale for Children, Fourth Edition), who was placed in a public school inclusion classroom where he received instruction with ten typically developing peers as well as three peers diagnosed with autism spectrum disorders. His parents had been divorced for several years, and Scott resided with his mother and younger brother. Scott had well-developed communication skills, as he used multi-word, complete sentences to communicate with others.

*Medication and Side Effects Profile.* Scott’s medication regimen included: aripiprazole (10mg/day administered in the morning and evening) and amphetamine salts (20mg/day administered in the morning and at noon). His mother stated that Scott’s medication combination had remained unchanged (i.e., stable dosages, no additional medications added) throughout the course of the study.

Scott's mother reported that since starting this combination of medications, she had noticed the presence of the following side effects: increased levels of intense irritability and agitation (i.e., akathisia), episodes of increased and intense negative affect (e.g., anger, crying spells), increased frequency of constipation, and decreased appetite. Specifically, she stated that her son appeared to be more physically agitated and restless, particularly in the late afternoon and early morning. She reported that during this time, Scott seemed to be increasingly bothered by certain visual and auditory stimuli, as he squinted his eyes when exposed to bright or flashing lights, he often held his hands over his ears, and yelled at his brother and mother if they made noises (e.g., sneezing, coughing, or laughing aloud) that were unexpected or that he perceived as being "too loud." She stated that while overall Scott's mood swings had noticeably been reduced since starting the medication, he continued to experience episodes during which he displayed more intense negative affect (e.g., he became excessively angry, "enraged," or would become extremely distressed and cry uncontrollably for extended periods of time). According to his mother, these episodes were more prevalent in the late afternoon/early evening, and as she recounted, they often occurred with seemingly minimal provocation. Additionally, his mother reported decreases in Scott's appetite during the day, as he often indicated that he was not hungry. Further, she stated that since going on the most current medications, he more frequently complained of gastrointestinal discomfort (e.g., bloating, gas, abdominal pain), likely associated with increased constipation (i.e., she noted that the frequency of his bowel movements had noticeably decreased).

*Context Selection.* During the initial phase of the study, Scott's mother completed the assessment measures, and was administered the SIAMSE. She reported that the

“homework routine” had become the most problematic routine for Scott since going starting the most current medication regimen (i.e., this routine was rated a 5 “much more difficult to complete,” on the 5-point Likert scale that measured the level of difficulty of home and community activities); thus, this routine was selected as the experimental context, and became the focus of the intervention. Specifically, his mother stated that when medication side effects were present, namely, increased irritability and agitation, episodes of excessive emotionality (crying spells), and more frequent gastrointestinal discomfort, they greatly impeded Scott’s ability to successfully complete the homework routine, and ultimately resulted in an exacerbation of problem behavior that was displayed in this context.

During the follow-up assessment, his mother explained that when Scott experienced increased levels of agitation and irritability, or when he appeared to experience intense episodes of negative affect or excessive emotionality (i.e., crying spells), he became more easily frustrated when presented with request or simple task demands. Similarly, she noted that when her son experienced increased discomfort caused by constipation and stomach cramping, he was much less tolerate of certain stimuli and was more easily bothered by minor annoyances. Additionally, his mother stated that he became increasingly more irritable and had greater difficulty concentrating or maintaining his attention on a particular task. Thus, she indicated that when these side effects were present, the homework routine subsequently became much more aversive and challenging for her son, and consequently, when Scott experienced greater difficulty completing this activity, he was much more likely to display severe levels of problem behavior (e.g., physical aggression directed at his mother and brother, property

destruction, tantrum behavior, and self-injurious behavior) in this context than had been the case prior to starting the current medication combination.

Additional activities were identified by Scott's mother as becoming more problematic since going on the medication when side effects were present, including the "dinnertime routine," as well as the "bedtime routine." These routines were identified as the clinical extension contexts, and although no formal data collection occurred in these contexts, several intervention strategies were taught to Scott and his family to address difficulties experienced.

*Participant 3: Robby*

Robby was a 14-year-old young man, diagnosed with Autistic Disorder (Full Scale IQ = 40, <0.1percentile, Stanford-Binet Scales of Intelligence, Fifth Edition), who lived at home with his mother and maternal grandmother. He attended a private school that served individuals with developmental disabilities. Robby communicated primarily using multi-word phrases and simple sentences, and he demonstrated delays with both expressive and receptive language skills.

*Medication and Side Effects Profile.* Robby's medication regimen while participating in the study included: risperidone (3mg/day, administered in the morning and evening); benztropine (2mg/day administered in the morning and evening); and valproic acid (500mg/day, administered in the morning and evening). His mother reported that he had been on this current combination of medication for the past several months, and that there had been no alterations in his medications throughout the course of the study (i.e., the drug dosages remained stable).

Robby's mother reported that her son appeared to experience a variety of side effects since the current combination of medications had been initiated including: increased levels of fatigue and general lethargy; greater levels of haziness or periods of cognitive dulling (e.g., difficulty concentrating, maintaining focus or sustained attention); psychomotor retardation (e.g., slowed speech output, slurred speech, delayed motor movements); and increased levels of anxiety. Specifically, she stated that Robby appeared to be much more lethargic and fatigued throughout the day (e.g., he looked physically drowsy, he was slower to respond to task demands), but this was particularly noticeable and bothersome for approximately 2 hours following medication administration, as he seemed to have great difficulty attending to tasks and remaining engaged. However, his mother reported that Robby became more alert and engaged later in the day; this pattern of lethargy and late-day alertness was also noted by his teachers. Further, his mother reported that he appeared to be much more anxious since going on the medication, as evidenced by marked increases in his obsessive compulsive type behaviors (e.g., perseverating on certain topics, engaging in repetitive ritualistic behaviors).

*Context Selection.* Robby's mother and grandmother participated in the initial assessment in which the SIAMSE was administered. According to their report, they noted that the "household chores routine" had become the most problematic routine for Robby since going on the most current medication regimen (i.e., this routine was rated a 5 "much more difficult to complete," on the 5-point Likert scale that measured the level of difficulty of home and community activities); thus, this activity was selected as the experimental context, and became the focus of the intervention. Specifically, his mother and grandmother stated that when medication side effects were present, namely,



increased levels of fatigue, psychomotor retardation, haziness/cognitive dulling, and elevated levels of anxiety, they greatly impeded Robby's ability to successfully complete the household chores routine, and ultimately resulted in an exacerbation of problem behavior that was displayed in this context.

During the follow-up assessment, his mother and grandmother explained that when Robby was fatigued, his physical movements were slow and sluggish; he was more likely to experience difficulty concentrating or episodes of "haziness," which further impacted his ability to complete tasks in a timely manner, and he became much more easily frustrated when presented with task demands and simple requests, particularly when he was asked to complete a disliked or difficult task than was the case prior to the current medication regimen. In addition, his mother stated that when he was lethargic, he often required greater levels of prompting and assistance to complete familiar activities. Further, his mother and grandmother reported that when Robby experienced elevated levels of anxiety, and engaged in rituals of repetitive behaviors, it became extremely difficult for him to focus or attend to tasks and to follow directions. Thus, they indicated that when these side effects were present, the household chores routine subsequently became much more aversive and challenging for Robby, and consequently, when he experienced greater difficulty completing this routine, he was much more likely to exhibit more severe levels of problem behavior (e.g., aggression, self-injurious behavior, property destruction, tantrums) than had been the case prior to the initiation of the most current medication combination.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional activities that had become more

problematic since going on the medication combination, seemingly due to the presence of side effects. These activities were identified as the clinical extension contexts, and included: “grooming” and “transitions between settings.” Although data collection did not occur in these contexts, Robby’s family was provided with additional mitigation and coping strategies to address difficulties encountered while completing these activities.

### *Baseline Observations*

As noted previously, baseline was divided into two components: an initial validation phase and an extended baseline phase. Following the completion of five validation sessions, each family entered the extended baseline phase. Throughout both baseline components, direct observations were conducted by multiple informants to confirm the presence of problem behavior in the experimental contexts and to assess ancillary dependent variables. For each family, one parent was identified as the primary parent rater, and was responsible for the ongoing data collection throughout the baseline and intervention conditions. A second caregiver was asked to conduct observations and collected data in the experimental contexts on multiple occasions during both components of baseline, as well as in the intervention condition. The investigator (first author) conducted multiple direct observations and collected data in the experimental contexts of all the participants to confirm that the specified routine was associated with the occurrence of problem behavior, and that a low percentage of transition steps were completed. In addition, on several occasions throughout both components of baseline, a second researcher, who was blind to the hypotheses of the study, also conducted direct observations and collected data in the experimental context. Data collected by the

primary parent raters in their respective experimental contexts during extended baseline and intervention phases are displayed in Figures 2-10.

A task analysis was developed for the experimental context identified for each participant, and was used to measure each child's completion of the problematic routines. Recall that Alexa's experimental context was "the mealtime routine;" thus, for Alexa, the sequence of mealtime routine steps was defined as follows: (1) Alexa came into the kitchen within 2 min of an adult delivering the verbal discriminative stimulus "It is time to set the table;" (2) Alexa set the table (i.e., put the plates, utensils, cups, and napkins in the appropriate places on the table); (3) Alexa sat down with her family and ate her meal for a minimum of 5 min without engaging in problem behavior or attempting to leave the kitchen; and (4) Alexa cleaned up her area (i.e., she threw out her garbage and put her plate, utensils, and cup in the sink) upon finishing her meal (or after remaining at the table for at least 5 min). For Scott, the homework routine was identified as the problematic context, and the sequence of steps for this activity was defined as follows: (1) Scott took his homework material out of his backpack and placed it on the kitchen table; (2) Scott completed his assignments; and (3) Scott removed all homework materials from the kitchen table. Robby's mother and grandmother had identified "household chores" as the experimental context, and the sequence of steps for this routine was defined as follows: (1) Robby entered the kitchen within 2 min of his mother or grandmother providing the verbal discriminative stimulus "It's time to start your housework;" (2) Robby created a list consisting of the two tasks he chose to complete (i.e., unloading the silverware from the dishwasher, cleaning the kitchen counters and table with Windex and paper towels, folding the laundry, or vacuuming the kitchen

floor); (3) Robby completed the first task on his list; and (4) Robby completed the second task on his list.

To ensure the safety of the child and the parent, a session was terminated contingent upon the demonstration of problem behavior defined as either : (1) the occurrence of a single instance of “untolerated” problem behavior, namely, aggression (e.g., hitting, dropping to the floor, kicking) or self-injurious behavior (e.g., biting hand, hitting head), or more than 5 seconds of screaming (Carr & Carlson, 1993), or (2) three instances of “tolerated” problem behavior, defined as brief episodes (i.e., less than 5 seconds) of screaming, verbal protests, and/or stomping feet on the floor. Tolerated problem behavior was seen as less serious by the parents and, thus, up to three instances of such behavior were allowed prior to the termination of the session.

#### *Response Recording*

During baseline and intervention sessions, data were collected by multiple informants (i.e., the primary parent rater, a second caregiver, the primary investigator, and a second researcher who was blind to the research hypotheses) to measure several primary dependent variables including: (a) percentage of task steps completed, (b) latency to session termination due to the occurrence of problem behavior or successful completion of the routine, and (c) the reason for session termination. Percentage of task steps completed prior to termination of the session (i.e., due either to the occurrence of problem behavior or successful completion of the activity) was determined by dividing the total number of steps required to complete the routine for each child, multiplied by 100 to yield a percentage of task steps completed. Latency to session termination was defined as the amount of time that elapsed after the first directive was given to begin the

first step in the task analysis and termination of the session due either to the occurrence of problem behavior or successful completion of the activity. Recall, sessions were terminated immediately upon the occurrence of a single instance of intolerated problem behavior, or three instances of tolerated problem behavior. The reason for session termination due to problem behavior comprised the third primary dependent variable.

Parent raters (i.e., the primary parent rater and a second caregiver) were asked to collect additional data in the experimental context, throughout baseline and intervention to measure several ancillary variables: (a) recordings that indicated whether side effects were present; (b) ratings of the level of intensity of the side effects (when present); (c) recordings that indicated whether the child experienced difficulty while participating in the problematic activity; (d) ratings of the level of difficulty experienced during completion of the home-based routine (when difficulty was noted); and (e) ratings of the overall level of severity of problem behavior displayed by the child in the experimental context. Using the Experimental Context Parent Ratings Form (Appendix F), parent raters recorded the presence (or absence) of medication side effects using a binary (Yes/No) measure; a 5-point Likert scale (values ranging from 1 “mild” to 5 “severe”), derived from question C-3 on the SIAMSE, was used to rate the level of intensity of the side effects that were present in the experimental context. Similarly, a binary (Yes/No) measure was used to record whether difficulty was experienced while attempting to complete the problematic routine, and when the routine was difficult, parents rated the level of difficulty using a 5-point Likert scale (values ranging from 1 “mild” to 5 “severe”), derived from question D-5 of the SIAMSE. The overall level of severity of problem behavior displayed in the experimental context was recorded using a 5-point

Likert scale (values ranging from 1 “mild” to 5 “severe”), derived from question E-2 of the SIAMSE.

### *Development of the Intervention*

Following a period of baseline, an intervention package was developed and subsequently implemented in each experimental context. Evidence-based practices were used to mitigate the negative impact of the side effects and to teach the child more effective coping skills to deal with these symptoms in order to reduce the level of difficulty experienced in the context, and, in turn, reduce the likelihood that problem behavior would occur. Once the intervention package was implemented in the experimental context, the investigator taught the families several additional strategies which they then implemented in the clinical extension contexts. The decision processes for initiating, continuing, and terminating the intervention in the experimental contexts are outlined in Appendix E. The rationale for implementing each component of the intervention packages for participants in all three studies is displayed in Appendix D.

Each family directly participated in the development of the unique intervention package that would be implemented in the experimental contexts they had identified. Although each package followed a generic model using mitigation and coping procedures, the precise nature of each strategy was determined by the specific properties of each context, including the characteristics of the various side effects that were present. A problem solving approach, as outlined in Appendix C, was used to obtain direct feedback from the parents regarding each of the strategies that were implemented in the problematic contexts. Interventions were implemented that the families considered user-

friendly and feasible, following procedures using the goodness of-fit assessment described in Appendix H(Albin et al., 1996).

*Participant 1: Alexa*

*Mitigation Strategies for Mealtime Routine.* Research has demonstrated that disliked or difficult routines may produce problem behavior (Clarke et al., 1995), and studies have suggested that problem behavior displayed during a non-preferred activity or routine may function as a means of terminating the aversive activity (Foster-Johnson, Ferro, & Dunlap, 1994). Data obtained from the initial assessment in Phase I of the study, and baseline observations suggested that the experimental context identified for Alexa (mealtime routine) was in fact a disliked routine that had become more difficult to successfully complete due to the presence of medication side effects. According to her parents, Alexa displayed signs of increased agitation, decreased tolerance for various environmental stimuli (e.g., verbal directives provided by her mother; the telephone ringing; the dog barking or whining, etc.), and marked irritability and anxiety while participating in the mealtime routine. Research has shown that *the use of a visual representation of upcoming events and/or steps in a given activity* can effectively reduce problem behavior, as visual schedules increase the predictability of the sequence of activities, thereby reducing some of the aversive aspects of the routine (Mesibov, Browder, & Kirkland, 2002). Therefore, we created a visual schedule of the several steps involved in the mealtime routine, to enhance the predictability of this non-preferred activity. Alexa was presented with a portable clipboard that displayed pictures depicting the sequence of steps involved in the routine. At the bottom of the board was a picture

representing an activity of her choice that she was permitted to engage in upon successfully complete the mealtime routine.

In addition to using visual supports to enhance predictability and reduce aversive qualities of disliked or difficult tasks, research has shown that *providing advanced verbal warnings* of upcoming difficult or disliked tasks also increase predictability, and are associated with reductions in problem behavior (Mace et al., 1998). Thus, providing Alexa with advanced warnings was included in the intervention package to mitigate the impact of contexts involving activities that she found aversive. For example, at 5 minutes and 1 minute prior to the start of the mealtime routine, Alexa's mother would provide verbal warnings about the upcoming activity such as, "In five minutes, it will be time to come to the kitchen to set the table."

According to the research, *embedding a preferred activity into a disliked activity or routine* has been found to be associated with decreases in problem behavior, as it likely reduces the aversiveness of the activity (Blair, Umbreit, & Bos, 1999). A preference assessment checklist (Matson et al., 1999) was administered to Alexa's parents to determine highly preferred activities. Listening to music on her iPod was identified as the most reinforcing activity, thus, this activity was embedded into various steps of the mealtime routine. Alexa was given the opportunity to choose songs to listen to on her iPod during the activity, and she was permitted to keep the music on provided she appropriately participated in the routine (i.e., she completed the task steps and refrained from engaging in problem behavior).

*Coping Strategies for Mealtime Routine.* Teaching *functional communication alternatives* to replace problem behavior has been shown to be an effective coping



strategy for reducing problem behavior (Carr & Durand, 1985; Carr et al., 1994; Durand, 1990). During the mealtime routine, Alexa was taught to verbally request a “break” if she started to feel agitated or was experiencing greater difficulty while engaging in any step of the routine. A visual “break card” was made available for Alexa to use as a reminder to appropriately indicate the need for a break. Initially, her parents provided prompts (verbal and gesture reminders to use the break card upon noticing the first signs of increasing agitation or frustration); however, after several sessions, the prompts were faded, and Alexa was independently requesting a break.

The use of *relaxation strategies* has been found to effectively reduce agitation and problem behavior displayed by individuals with developmental disabilities (Mullins & Christian, 2001). As noted previously, Alexa’s parents identified increased levels of irritability, agitation, and anxiety as likely medication side effects experienced during the mealtime routine. Thus, to address these affective symptoms that she experienced during the mealtime routine, portions of a cognitive-behavioral therapy manual, *The Coping Cat* (Kendall & Hedtke, 2006), were used to teach Alexa to correctly identify somatic signs of agitation and anxiety. Additionally, she was taught to use several cognitive and behavioral methods to more effectively cope with these feelings. For example, Alexa created lists of activities that she could engage in to distract herself when she noticed increased signs of agitation or anxiety (e.g., listening to music, thinking about her favorite movie, recalling a humorous story or joke), and relaxation techniques she could use when she felt upset (e.g., deep breathing exercises). Deep breathing techniques, as described by Cautela & Gorden (1978) were taught to both Alexa and her parents, as a

means of physically reducing or eliminating physiological symptoms associated with anxiety and agitation.

*Clinical Extension.* Alexa's parents had identified two additional activities that had become more difficult to successfully complete due to the presence of medication side effects, resulting in greater levels of problem behavior and negatively impacting family quality of life. While no experimental demonstration was included in these contexts, additional mitigation and coping strategies were developed and implemented to address problem behavior. Specifically, Alexa's parents reported that (a) grooming, and (b) the homework routine had become more problematic since going on the medication regimen, as side effects were present and likely made these activities more difficult to complete. Disliked and difficult routines have been found to be associated with increased problem behavior in individuals with developmental disabilities in the literature (Clarke et al., 1995; Flannery & Horner, 1994). A visual schedule of upcoming events or the sequence of tasks in an activity has been shown to effectively reduce problem behavior because schedules enhance the predictability of the routine (Mesibov et al., 2002). Therefore, we created visual schedules that were comprised of written lists of the steps for each activity. Additionally, research has suggested that providing assistance during difficult activities is associated with reductions in problem behavior (Reichle, Drager, & Davis, 2002). Therefore, when her parents noticed that she was experiencing any of the aforementioned side effects during the grooming or homework routines, they would provide Alexa with additional support to reduce the level of difficulty. For example, her mother provided instructional support and relevant verbal prompts (e.g., reminders to use her schedule to remain on-task) if Alexa was having difficulty completing an assignment.

Furthermore, Piazza, Contrucci, Hanley, & Fisher (1997) demonstrated that providing nondirective prompting and continuous noncontingent access to attention and positive reinforcement effectively reduced problem behavior associated with hygiene routines. Thus, during the grooming routine, when side effects were present, Alexa's mother delivered nondirective prompts (i.e., verbal suggestions, cues, or physical gestures that introduced or provided information about the next step in the routine to be completed), and provided access to reinforcement throughout the various steps in the activity (e.g., listening to music).

*Participant 2: Scott*

*Mitigation Strategies for Homework Routine.* Research has demonstrated that increased anxiety and agitation may be associated with problem behavior exhibited by individuals with developmental disabilities (Rojahn, Matson, Naglieri, & Mayville, 2004). Data gathered from the initial assessment in Phase I of the study, and baseline observations suggested that the experimental context identified for Scott (homework routine) was in fact a problematic activity that was in fact difficult to successfully complete due to the presence of medication side effects. While completing his homework, his mother noted that Scott often displayed signs of agitation and anxiety (e.g., he was unable to remain seated and maintain his attention on the task, he threw his papers and books off the table, perseverated on minute details of the assignment, and was unable to complete his work), thus, strategies were implemented to mitigate various aspects of the problematic routine. The use of a *visual schedule of upcoming events and the sequence of tasks within an activity* has been shown to effectively reduce problem behavior exhibited by individuals with developmental disabilities, by enhancing

predictability (Mesibov et al., 2002). Therefore, to increase the predictability of the homework routine, we created a visual schedule (i.e., a written “to do” list) that outlined the sequence of tasks that Scott needed to complete. Each afternoon, Scott’s mother would review his assignments, and would work with him to create a written list of the various tasks that needed to be completed. She reported that Scott enjoyed making lists, thus, we incorporated this interest into the intervention package. As he completed each task, Scott would place a checkmark next to the item on his schedule, further enhancing the predictability of the routine.

Activities that are too long have been found to be associated with an increase in problem behavior in individuals with developmental disabilities (Sweeny & LeBlanc, 1995). According to his mother, the presence of medication side effects had negatively impacted the homework routine, and often prolonged the duration of this activity. Therefore, to reduce the difficulty Scott had been experiencing during this routine, we *modified the activity* by dividing his homework tasks into shorter, more manageable portions. Studies have demonstrated that intervention packages that include *interspersing tasks* and *embedding procedures* effectively reduce problem behavior displayed by individuals with developmental disabilities (Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991; Carr, Newsom, & Binkoff, 1980). Therefore, each afternoon, Scott’s mother reviewed all of his assignments and separated the tasks so that he would complete easier ones prior to being presented with more difficult tasks.

Studies have demonstrated that *providing verbal warnings or reminders* to signal the duration of an activity decreases problem behavior (Mace et al., 1998). Therefore, in addition to the use of the visual schedule to enhance predictability, a verbal reminder was

included as part of the intervention package to mitigate one of the negative aspects (i.e., the duration of the activity) of the homework routine. Scott was given verbal reminders by his mother about the number of task steps remaining in the activity, and he was provided with a verbal reminder about the preferred activity that he could engage in upon completion of his homework. For example, when his mother noticed he was becoming restless or when he was nearing the end of the tasks he was expected to complete, she reminded him that he was almost finished and alerted him to an upcoming preferred activity, such as, “two more spelling sentences and homework will be all done, then you get to play on the computer.”

*Coping Strategies for Homework Routine.* Research has suggested that providing assistance during difficult tasks has been associated with a decrease in problem behavior (Reichle, et al., 2002). According to his mother, Scott had experienced greater difficulty completing homework when medication side effects were present, resulting in an exacerbation of problem behavior. Replacing problem behavior with *functionally equivalent communication skills* has been shown to reduce or eliminate problem behavior (Carr & Durand, 1985). Therefore, Scott was taught to verbally request help from his mother when he was experiencing difficulty. A visual “help me” card was displayed on his table throughout the routine, serving as a reminder to use his replacement skill (i.e., verbal request for help) rather than problem behavior when he needed help. His mother would prompt Scott to request help (e.g., she pointed to the “help me” card) if she noted that he was beginning to experience difficulty while completing any part of his assignments.

As noted previously, research has demonstrated that the use of *relaxation strategies* is associated with decreased agitation and problem behavior (Mullins & Christian, 2001). As a strategy for dealing with increased levels of irritability, agitation, and frustration experienced while completing his homework, Scott was taught several relaxation strategies including deep breathing and progressive muscle relaxation (Cautela, & Groden, 1978). Upon noticing signs of increasing frustration, his mother prompted him to use his relaxation techniques. A visual book that depicted several relaxation exercises was kept within Scott's view during the routine, so that he could refer to it as an additional visual support to help him relax.

*Clinical Extension.* Scott's mother had also identified three additional contexts in which medication side effects were present, and that had become more difficult to complete: (a) the mealtime routine, (b) playing with his sibling, and (c) the bedtime routine. Mitigation and coping skill strategies were developed and implemented to reduce problem behavior displayed by Scott in these contexts. According to his mother, Scott's appetite had substantially decreased since going on medication, and she noted that mealtimes had become increasingly problematic, as he often refused to eat, stating that he was not hungry. Studies have demonstrated that including *opportunities for making choices* in an activity or routine significantly reduces problem behavior (Shogren, Faggella-Luby, Jik Bae, & Wehmeyer, 2004). Therefore, to enhance his motivation and increase the likelihood that he would eat dinner with his family, we gave him opportunities to make choices regarding the food his mother made for him to eat for dinner. Including preferred foods and incorporating more frequent opportunities for

making choices about various aspects of the meal, reduced some of the more aversive features of this problematic routine.

Having a disagreement with others has been found to be associated with elevated rates of problem behavior displayed by individuals with developmental disabilities (Gardner, Cole, Davidson, & Karan, 1986). Scott's mother reported that since going on the current medication regimen, he had become much more irritable and more easily frustrated when playing with his younger brother, and often displayed problem behavior related to arguments over access to the family television, taking turns on the family computer, and sharing video games. Visual schedules have been found to increase predictability and are associated with reductions in problem behavior (Mesibov et al., 2002). As noted previously, Scott enjoyed making lists; therefore, a visual "turn-taking" schedule was created and used to provide organization and increased predictability during activities that involved taking turns while playing with his brother.

Evidence suggests that the prevalence of sleep disturbances experienced by children with developmental disabilities is higher than in typically developing children (Richdale, Gavidia-Payne, Francis, & Cotton, 2000). Further, studies have shown that sleep disturbances are often associated with greater levels of problem behavior (Durand, Gernert-Dott, & Mapstone, 1996; Kennedy & Meyer, 1996; Wiggs & Stores, 1996). Several behavioral procedures have been found to be effective in reducing disruptive sleep patterns in children with developmental disabilities, including the use of *positive bedtime routines* (Christodulu & Durand, 2004). The bedtime routine was identified as one of the clinical extension contexts by Scott's mother, as she reported the presence of medication side effects (e.g., insomnia, increased irritability) and increased levels of

problem behavior. Assessment revealed that there was no consistent bedtime routine in place, and Scott frequently fell asleep at variable times, and often in different locations around the house (e.g., his mother's bedroom, the living room). To address this problematic context, we worked in conjunction with Scott's mother to develop a clear plan to make the bedtime routine more predictable and consistent. The plan consisted of a series of relaxing activities that included taking a shower, changing into pajamas, and reading a story in bed with his mother. The order and timing of the activities remained the same; the routine was started at approximately 9:00 p.m. each evening and Scott was awoken each morning at 6:00 a.m. to help maintain a consistent sleep/wake cycle.

*Participant 3: Robby*

*Mitigation Strategies for Household Chores.* Research has shown that children with developmental disabilities may display a variety of problem behavior when presented with a difficult or disliked activity (Carr, Newsom, & Binkoff, 1980; Clarke et al., 1995; Miltenberger, 2006). Data gathered from the initial assessment in Phase I of the study, and baseline observations suggested that the experimental context identified for Robby (household chores) was in fact a problematic activity that was difficult for him to successfully complete, due to the presence of side effects. Although he had experienced some difficulty while participating in these tasks in the past, his mother and grandmother noted that since going on the most current combination of medication, completing his household chores had become extremely difficult, and, in turn, he typically displayed severe levels of problem behavior when engaging in this activity. Several mitigation strategies were developed and implemented to address the difficulties that Robby was experiencing when side effects were present during this routine. As noted previously,



*visual schedules* have been found to be associated with reductions in problem behavior displayed by individuals with developmental disabilities (Mesibov, et al., 2002; Krantz, MacDuff, & McClannahan, 1994). Presumably, the use of visual supports enhances predictability of upcoming events, provides the individual with greater structure and organization helps the individual make sense of their environments, and allows them to comprehend expectations placed on them (Heflin & Simpson, 1998). Therefore, we created a visual schedule for Robby that depicted the various tasks that he was expected to complete during the household chores routine. Picture icons were used to represent each task, and were posted to a portable board that Robby could carry around with him as he completed each step. Upon completing a task, Robby was taught to remove the picture icon representing the task, and place it in the “finished” envelope fastened to the back of the board. A picture of a chosen reinforcing item or activity was placed at the bottom of his schedule, and served as a visual reminder of the preferred activity/item he could access upon completing his tasks.

Research has shown that presenting individuals with *shorter tasks* may produce increased levels of productivity, and lower levels of problem behavior (Sweeney & LeBlanc, 1995). Therefore, in conjunction with his mother and grandmother, we created a plan for the household chores routine that involved breaking up the routine into smaller steps that would take less time to complete. Robby would still be expected to complete the same amount of work over the course of the afternoon and evening (i.e., complete the same number of household chores as he had previously been expected to do); however, we ensured that the tasks were kept short (i.e., lasting no longer than 5 or 7 minutes each), and that we presented him with easier tasks first to enhance his motivation and

increase the likelihood that he would continue working on a more difficult portion of the task. Research has suggested that incorporating easier tasks or an individual's personal preferences early in an activity sequence can create a *behavioral momentum*, and, in turn, reduce the likelihood that problem behavior will occur (Bambara, Koger, Katzer, & Davenport, 1995; Blair, Umbreit, & Bos, 1999; Clarke et al., 1995; Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991).

In addition to using behavioral momentum procedures, we included frequent *opportunities for choice-making* throughout the household chores routine. According to the research, including opportunities for choice in activities has been found to decrease problem behavior exhibited by individuals with developmental disabilities (Shogren et al., 2004). Therefore, we incorporated multiple opportunities for Robby to make choices throughout the activity. For instance, prior to the start of the activity, Robby was asked to choose the two tasks that he would complete (from a list of four options) and the order in which he would complete them. Additionally, Robby was given a choice of a preferred activity to engage in upon completion of the two tasks (e.g., read a book, watch television, or listen to music).

*Coping Strategies for Household Chores.* Research has suggested that providing assistance during difficult tasks has been associated with a decrease in problem behavior (Reichle et al., 2002). According to his mother, Robby had experienced greater difficulty completing his household chores (e.g., unloading the dishwasher, cleaning the kitchen counters and table, folding laundry, and vacuuming the floor) when medication side effects were present, resulting in an exacerbation of problem behavior. Studies have demonstrated that replacing problem behavior with *functionally equivalent*

*communication skills* has been shown to reduce or eliminate problem behavior (Carr & Durand, 1985). Therefore, Robby was *taught to verbally request help* from his mother when he was experiencing difficulty. A visual “help me” card was displayed on his schedule board that he kept near him at all times throughout the routine. This card served as a reminder to use his replacement skill (i.e., verbal request for help) rather than problem behavior when he needed help. His mother provided gesture prompts to remind Robby to request help (e.g., she pointed to or handed him the “help me” card) if she noted that he was beginning to experience difficulty while completing any part of his tasks.

Additionally, if Robby became overly distressed or frustrated during the household chores routine, he was *taught to request a short “break.”* He was provided with the two options for his “break time” that included resting on the couch for several minutes to relax, or sitting in a chair and practicing his deep breathing exercises (described below). A visual timer was used to represent the amount of time that remained before his break ended, thus, increasing predictability.

As noted previously, research has demonstrated that the use of *relaxation strategies* is associated with decreased agitation and problem behavior (Mullins & Christian, 2001). As a strategy for dealing with increased levels of anxiety, and irritability while completing his household chores, Robby was taught two relaxation strategies including a deep breathing and a modified version of a progressive muscle relaxation exercise (Cautela, & Groden, 1978). Upon noticing signs of increasing frustration, his mother prompted him to use his relaxation techniques. A visual book that depicted several relaxation exercises was kept near him (i.e., within view) during the routine, so that Robby could refer to it as an additional visual support to help him relax.

*Clinical Extension.* Robby's mother and grandmother had identified two additional contexts in which medication side effects were present, and that had become more difficult to successfully complete: (a) transitions between settings and/or activities, and (b) the grooming routine. Mitigation and coping skill strategies were developed and implemented to reduce problem behavior displayed by Robby in these contexts. Transitions between settings and/or activities have been found to produce problem behavior (Schmit, Alper, Raschke, & Ryndak, 2000). Research has suggested that the lack of predictability associated with transitions plays a large role in evoking problem behavior (Flannery, & Horner, 1944). As transitioning between locations had become much more problematic for Robby, due to the presence of medication side effects, we developed and implemented a visual schedule of upcoming events, as studies have demonstrated the efficacy of activity schedules to enhance the predictability associated with the transition (Dettmer, Simpson, Smith-Myles, & Ganz, 2000; Mesibov et al., 2002). Robby was presented with a portable board (clipboard) that had pictures representing locations he would be traveling to in the community and at school. As he became more familiar with the sequence involved in the transitions, we were able to modify the board, and create a smaller wallet sized picture schedule that was clipped onto his belt and referenced it when needed.

According to Robby's mother and grandmother, the grooming routine had become increasingly more difficult for Robby to successfully complete, presumably due to the presence of the medication side effects (e.g., fatigue, haziness, irritability, agitation). As noted previously, visual schedules have been found to be highly effective in addressing problem behavior related to difficult activities (such as grooming), as

schedules provide more structure to the activity, and increase predictability (Dettmer et al., 2000). To address difficulties experienced in this routine, we created a visual schedule that depicted the sequence of steps for each of the grooming tasks (i.e., brushing teeth, and brushing hair). The schedules were posted on the wall in Robby's bathroom so that he could easily access them and use them when needed. Upon completion of the grooming routine, he was provided with a choice of two highly preferred activities to engage in (e.g., watch a favorite video or listening to a book on tape) to further increase the likelihood that he would appropriately complete the routines.

#### *Training of the Intervention Agent*

Once the intervention package was developed, the investigator trained the intervention agents (for Alexa, her mother and father; for Scott, his mother; and for Robby, his mother and grandmother) to carry out the intervention package. The investigator provided a verbal explanation of the procedures and then modeled the use of each of the strategies with the child for a minimum of two sessions. A written description of the intervention components was given to each intervention agent to use, as needed, as an additional form of support. The intervention agent implemented the multicomponent intervention package with verbal feedback from the investigator for one session. Verbal feedback was faded, as the intervention agent implemented the intervention package independently for a minimum of two sessions.

#### *Intervention Implementation*

The purpose of this phase was to evaluate whether the implementation of the multicomponent intervention package in the experimental context resulted in a measurable decrease in the level of difficulty the child experienced in the priority routine,

which would, in turn, lead to an increase in the percentage of task steps that were completed, as well as a reduction in problem behavior that was displayed. During the intervention condition, each family implemented the multicomponent intervention package in their respective experimental contexts, and data were collected by the primary parent rater, a second caregiver, the investigator, and a second researcher for the various dependent variables described previously. In addition, measures were collected by the primary parent rater and the primary investigator to assess the use of each intervention component (i.e., independent variable integrity).

#### *Intervention Fidelity*

An intervention fidelity checklist (Appendix I, Intervention Integrity Checklist), based on the treatment plan designed for each participant, was developed to evaluate intervention integrity in the experimental context. For each participant, a checklist was created that was uniquely tailored to the strategies developed for their problematic routine. In 100% of the baseline sessions and 75% of the intervention sessions for Alexa, in 50% of the baseline sessions and 71% of the intervention sessions for Scott, in 64% of the baseline sessions and 57% of the intervention sessions for Robby, the primary parent raters for each participant and the investigator recorded whether each intervention component was implemented. That is, the primary parent rater and the investigator completed the fidelity checklist by recording a checkmark whenever a specific strategy was implemented by the parent in the experimental context.

#### *Inter-rater Reliability*

As noted previously, multiple informants conducted direct observations and collected reliability data on the independent and dependent variables in the experimental

contexts identified for each participant. A binary reliability index was used to assess agreement between the primary parent rater and the investigator on intervention fidelity, and on the primary dependent variables including: the percentage of context steps completed, latency to session termination, and the reason for session termination. For each session, reliability was scored as either perfect agreement or no agreement. Agreement was defined as both observers recording the implementation of the intervention components, the same number of task steps completed in the context that they observed, latency measures that were within 5 seconds of one another, and agreement on the reason for session termination (i.e., due to the occurrence of problem behavior or successful completion of the activity).

In addition to collecting reliability data on the primary dependent variables, the primary parent rater and the second caregiver rater collected reliability data on the ancillary dependent variables including: the presence of medication side effects, ratings of the level of intensity of the side effects, the presence of difficulty experienced in the problematic routine, ratings of the level of difficulty experienced, and ratings of the overall level of problem behavior severity displayed by the child in the priority context. A binary reliability index was used to assess agreement on all of the dependent variables; thus, for each session, reliability was scored as either perfect agreement or no agreement. The same parameters that were outlined above were used to define agreement for the primary dependent variables. For the ancillary dependent variables, agreement was defined as both raters recording whether the side effects were present during the routine (i.e., indicating either “Yes” when side effects were present, or “No” when side effects were absent), recording the same rating of the level of intensity of the side effects that

were present in the observed context (using a 5-point Likert scale), agreement on whether the routine was difficult for the child to complete (i.e., indicating either “Yes” when the activity was difficult, or “No” when it was not difficult), recording the same rating of the level of difficulty experienced in that problematic routine (using a 5-point Likert scale), and recording the same rating of the overall level of problem behavior severity displayed by the child (using a 5-point Likert scale).

A binary reliability index was used to assess the agreement between data recorded by the primary investigator and the second researcher on the percentage of context steps completed, latency to session termination, and the reason for session termination (due to problematic behavior or successful completion of the activity). For each session, reliability was scored as either perfect agreement or no agreement, and agreement was defined using the same parameters that were described previously for these primary dependent variables.

*Participant 1: Alexa*

For the experimental context, the primary parent rater and the investigator independently (but concurrently) completed reliability checks for 100% of the baseline sessions and 75% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 80% of both the baseline and intervention sessions. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of



the baseline and intervention sessions. Agreement on the ancillary dependent variables including the presence/absence of side effects, ratings of the level of side effects, the presence/absence of difficulty in the experimental context, the ratings of the level of difficulty experienced, and the ratings of the level of problem behavior severity was noted in 100% of the baseline and intervention sessions.

For 40% of the baseline sessions, and 45% of the intervention sessions, reliability checks were independently (but concurrently) completed by the primary investigator and the second researcher. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

*Participant 2: Scott*

For the experimental context, the primary parent rater and the investigator independently (but concurrently) completed reliability checks for 50% of the baseline sessions and 71% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 63% of the baseline sessions and 65% of the intervention sessions. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on the ancillary dependent variables including the presence/absence of side effects, the presence/absence of difficulty in the experimental context was noted in 100% of both the baseline and

intervention sessions. Agreement on ratings of the level of intensity of side effects that were present in the experimental context was noted in 100% of the baseline sessions and 82% of the intervention sessions. Agreement on the ratings of the level of difficulty experienced and on the ratings of the level of problem behavior severity was noted in 100% of the baseline sessions and 91% of the intervention sessions.

For 38% of the baseline sessions and 41% of the intervention sessions, reliability checks were independently (but concurrently) completed by the investigator and the second researcher. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of the baseline and intervention sessions.

*Participant 3: Robby*

For the experimental context, the primary parent rater and the investigator independently (but concurrently) completed reliability checks for 64% of the baseline sessions and 57% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 100% of the baseline sessions and 88% of the intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 69% of the baseline sessions and 64% of the intervention sessions. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of the baseline and intervention sessions. Agreement on the ancillary

dependent variables including the presence/absence of side effects, presence/absence of difficulty in the experimental context, and the ratings of the level of difficulty was noted in 100% of the baseline and intervention sessions. Agreement on the ratings of the level of intensity of side effects that were present was noted in 86% of the baseline sessions and 100% of the intervention sessions. Agreement on the ratings of the level of problem behavior severity was noted in 100% of the baseline sessions and 89% of the intervention sessions.

For 45% of the baseline sessions and 50% of the intervention sessions, reliability checks were independently (but concurrently) completed by the investigator and the second researcher. Agreement on the percentage of context steps completed, and reason for session termination was noted in 100% of both the baseline and the intervention sessions. Agreement on latency to session termination was noted in 80% of the baseline sessions and 100% of the intervention sessions.

## Results

### *Intervention Fidelity*

In baseline, a mean of 0% of the intervention components were implemented by each parent in their respective experimental contexts. During intervention, for the experimental contexts, a mean of 100% of the intervention components were implemented by each respective parent.

### *Percentage of Steps Completed*

The percentage of home-based routine steps completed in the extended baseline and intervention phases for each participant is displayed in Figure 2. In baseline, Alexa completed a mean of 10% of the steps that comprised the mealtime routine, completing

only 25% of the steps in 4 out of 10 sessions. However, during intervention, she completed 100% of the steps in 18 out of 20 sessions, and 75% of the steps in the remaining two sessions. In baseline, Scott completed a mean of 16.5% of the steps that constituted the homework routine. However, during intervention, he completed 100% of the steps in 14 out of 17 sessions and 66% of the steps in the remaining three sessions. In baseline, Robby completed a mean of 15.9% of the steps that constituted the household chores routine. During intervention, however, he completed a mean of 100% of the steps in 11 out of 14 sessions, and a mean of 67% of the steps in the remaining three sessions.

#### *Latency to Problem Behavior*

Figure 3 displays data on the amount of time that elapsed before the session was terminated (due to the occurrence of problem behavior or successful completion of the routine) for the three participants. For Alexa, the mean latency to problem behavior displayed during the mealtime routine in baseline was 2 min, 55 s. The mean latency to problem behavior during intervention was 11 min, 3 s in the two sessions that were terminated, and mean latency to successful completion of the mealtime routine (18 out of 20 sessions) was 15 min, 5 s. For Scott, the mean latency to problem behavior demonstrated during the homework routine in baseline was 4 min, 11 s. The mean latency to problem behavior during intervention was 11 min, 13 s in the three sessions that were terminated, and mean latency to successful completion of the homework routine (14 out of 17 sessions) was 16 min, 52 s. For Robby, the mean latency to problem behavior displayed while participating in the household chores routine in baseline was 2 min, 37 s. During intervention, the mean latency to problem behavior was 8 min, 16 s in the three

sessions that were terminated, and mean latency to successful completion of the household chores routine (11 out of 14 sessions) was 12 min, 31 s.

#### *Reason for Session Termination*

Figure 3 shows that sessions could be terminated due to the presence of intolerated problem behavior (indicated by solid black bars), tolerated problem behavior (indicated by solid pink bars), or successful completion of the problematic home-based routine in the absence of problem behavior (indicated by open bars). For each participant in baseline, all sessions were terminated due to the presence of problem behavior (i.e., none of the baseline sessions were successfully completed). During intervention for Alexa, only 2 out of the 20 sessions were terminated due to tolerated problem behavior (as indicated by pink bars); thus, the remaining 18 sessions were successfully completed. For Scott, 3 out of the 17 intervention sessions were terminated due to tolerated problem behavior, and the remaining 14 sessions were successfully completed. For Robby, 3 out of 14 sessions were terminated due to tolerated problem behavior, and the remaining 11 sessions were successfully completed in the absence of problem behavior. Thus, following intervention, no session had to be terminated due to intolerated (serious) problem behavior for any of the participants in Study 1.

#### *Presence or Absence of Medication Side Effects*

For each participant, a binary (yes/no) measure was used to document the presence (or absence) of the medication side effects experienced in their respective home-based experimental context. The primary parent raters for all three participants indicated that medication side effects were in fact present (at elevated levels) in 100% of the sessions throughout the extended baseline and intervention phases, as evidenced by data

presented in Figure 4 which displays ratings of the level of side effect intensity for each participant in Study 1.

#### *Level of Intensity of Medication Side Effects*

As previously noted, parents were asked to rate the level of intensity of the medication side effects that were present in the experimental context, using a 5-point Likert scale (values ranging from 1 “mild” to 5 “severe”). Figure 4 displays ratings provided by primary parent raters of the level of intensity of the various side effects that participants experienced in their problematic home-based routines. For all three participants, side effect intensity ratings were in the *severe* range (i.e., level of intensity was rated a 4 or 5 on the 5-point Likert scale) for all sessions throughout the baseline and intervention phases. The mean rating of the level of intensity of side effects experienced by Alexa was 4.6 in baseline and 4.7 during intervention. For Scott, the mean rating of the level of intensity of side effects was 4.6 in both baseline and intervention. The mean rating of the level of intensity of the side effects experienced by Robby in his experimental context was 4.6 in baseline and 4.5 during intervention.

#### *Presence or Absence of Difficulty in the Experimental Context*

For each participant, a binary (yes/no) measure was used to document the presence (or absence) of difficulty experienced while participating in the problematic home-based experimental context. Throughout all sessions in the extended baseline phase, the primary parent raters for all three participants indicated that their respective experimental context was indeed more difficult for their child to successfully complete (i.e., in 100% of the baseline sessions, difficulty was noted in the experimental contexts), as evidenced by data presented in Figure 4 which displays ratings of the level of

difficulty for each participant in Study 1. For Alexa, difficulty was noted in 40% of the intervention sessions (i.e., 8 out of 20 sessions); however, in 60% of the sessions, her father indicated that there was no difficulty present while completing the mealtime routine. For Scott, difficulty was noted in 47% of the intervention sessions (i.e., 8 out of 17 sessions); however, his mother indicated that there was no difficulty present while completing the homework routine in 53% of the sessions. For Robby, difficulty was noted in 50% of the intervention sessions (i.e., 7 out of 14 sessions); however, in 50% of the sessions, his mother indicated that there was no difficulty present while completing the household chores routine.

#### *Level of Difficulty Experienced in the Experimental Context*

As previously described, parents were asked to indicate whether the experimental context was difficult to successfully complete, and for the sessions in which difficulty was noted, they provided ratings of the level of difficulty experienced, using a 5-point Likert scale (values ranging from 1 “mild” to 5 “severe”). Figure 4 displays the level of difficulty ratings for each participant in Study 1. For all three participants, the level of difficulty experienced while completing their respective home-based experimental context was rated in the *severe* range (i.e., level of difficulty ratings of 4 or 5 on the 5-point Likert scale) for 100% of the extended baseline sessions. For Alexa, all of the sessions in baseline were identified as being difficult to complete, and the mean rating of the level of difficulty was 4.8. During intervention, the mean rating of the level of difficulty for the eight sessions that were identified as being difficult to complete was 1.8; thus the mean rating fell within the *mild* range on the 5-point Likert scale. In baseline for Scott, difficulty was noted in all sessions, and the mean rating of the level of difficulty

was 4.9. During intervention, however, only eight sessions were identified as being difficult to complete, and the mean rating of the level of difficulty for these sessions was 1.6; thus, the mean rating fell within the *mild* range on the 5-point Likert scale. For Robby, all of the baseline sessions were identified as being difficult to complete, and the mean rating of the level of difficulty was 4.6. During intervention, difficulty was noted in seven sessions, and the mean rating of the level of difficulty was 1.9; thus, the mean rating fell within the *mild* range on the 5-point Likert scale.

#### *Overall Level of Problem Behavior Severity*

Parents were asked to rate the level of severity of the problem behavior exhibited by their child in their respective home-based experimental contexts, using a 5-point Likert scale (values ranging from 1 “mild” to 5 “severe”). Figure 4 displays parent ratings of the level of problem behavior severity for each participant in Study 1. Throughout all of the extended baseline sessions, parents reported that their child demonstrated *severe* levels of problem behavior in their problematic routines (i.e., the level of severity was rated either a 4 or 5 on the 5-point Likert scale). For Alexa, problem behavior was displayed in all sessions of the extended baseline phases, and the mean rating of the level of problem behavior severity was 4.4. However, during intervention, problem behavior was demonstrated in 11 out of 20 sessions, and the mean rating of the level of severity for these sessions was 1.7, which fell within the *mild* range on the 5-point Likert scale. For Scott, problem behavior was exhibited in all extended baseline sessions; the mean rating of the level of problem behavior severity was 4.6. During intervention, however, he displayed problem behavior in only 8 out of 17 sessions, and the mean rating of the level of severity for these sessions was 1.5, which fell within the *mild* range on the 5-point



Likert scale. Problem behavior was demonstrated by Robby in all extended baseline sessions, and the mean rating of the level of problem behavior severity was 4.5. During intervention, he exhibited problem behavior in 7 out of 14 sessions, and the mean rating of severity was 1.9, which fell within the *mild* range on the 5-point Likert scale. In sum, following intervention, the number of sessions in which problem behavior was displayed had been substantially reduced for all participants.

## STUDY 2: COMMUNITY-BASED ROUTINES AS A CONTEXT FOR PROBLEM BEHAVIOR

### Method

#### *Overview*

All the procedures outlined in the Overview section of Study 1 were repeated in Study 2 for a different group of families. This process resulted in the selection of three participants, ranging in age from 11 to 14 years old, for whom families identified a community-based routine as the priority (experimental) context (i.e., the activity that had become more problematic for their child since going on their current medication, due to the presence of side effects and ultimately resulting in an exacerbation of problem behavior). Specifically, the experimental contexts included: for Jack “eating in restaurants,” for Ellie, “going to the grocery store,” and for Neil, “going to weekly doctor appointments.”

A multiple baseline design across three participants (Hersen & Barlow, 1976) was conducted in Study 2 to examine the potential impact of an intervention package, comprised of mitigation and coping strategies, on problem behavior displayed during problematic community-based routines.

## *Participant and Context Selection*

### *Participant 1: Jack*

Jack was a 12-year-old boy, diagnosed with Autistic Disorder (Full Scale IQ = 60, Leiter International Performance Scale-Revised), who lived at home with his parents, older brother, and younger sister. He attended a private school that served individuals with developmental disabilities. Jack communicated verbally, using multi-word, simple sentences and phrases, and had a history of displaying immediate and delayed echolalia.

*Medication and Side Effects Profile.* Throughout the course of the study, Jack's medication regimen included: risperidone (3mg/day administered in the morning and evening); clomipramine hydrochloride (100mg/day, administered in the morning and evenings); and lorazepam (2mg/day administered in evening and used PRN during the day as needed for increased anxiety). According to his parents, Jack had been on this current combination of medication, without changes in dosage, for the past 6 months.

His parents reported that since going on this medication regimen, they noticed the presence of the following side effects: increased fatigue, haziness (i.e., reduced ability to focus, difficulty concentrating); elevated levels of irritability and agitation; and increased appetite. Specifically, his mother reported that Jack appeared to become more noticeably fatigued (i.e., he appeared physically drowsy, frequently attempted to lie down) shortly after taking the medication. She noted that he became more lethargic within 20-30 minutes upon administration, and this typically lasted approximately 2 hours, after which he usually became more alert and energetic. His mother reported that Jack appeared to have more difficulty concentrating or maintaining focus, and that he seemed to experience periods of increased haziness, particularly evident when he was fatigued

following administration of his medication. She also noted that her son was much more irritable and easily agitated, most often in the later afternoons and in the evenings, as she said that he often became excessively distressed and easily disturbed over minor annoyances and was more readily irritated by certain environmental stimuli (e.g., crowded or noisy settings, loud or unexpected sounds). Additionally, she stated that both she and his father noticed a substantial increase in his appetite, as he ate much larger portions of food, frequently stated that he was hungry and requested food throughout the day, and according to his mother, he had gained approximately 15-20 pounds over the past 6 months.

*Context Selection.* During the initial phase of the study, Jack's mother completed the assessment measures, and was administered the SIAMSE. She indicated that eating out in restaurants had become the most problematic routine for her son since starting the current medication regimen (i.e., this routine was rated a 5 "much more difficult to complete," on the 5-point Likert scale that measured the level of difficulty of home and community activities); thus, this routine was selected as the experimental context, and became the focus of the intervention. Specifically, his mother stated that when medication side effects were present, namely, elevated levels of fatigue, increased haziness, irritable mood/agitation, and increased appetite, they greatly interfered with Jack's ability to successfully complete the eating in restaurants routine (an activity that was highly valued by the family), and ultimately led to an exacerbation of problem behavior displayed in this context.

During the follow-up assessment, Jack's mother explained that when her son became lethargic and fatigued, activities and tasks became more difficult for him, as his

motor movements and responses became noticeably slower and more sluggish; he seemed to have more difficulty concentrating or maintaining his focus/attention to tasks and activities; and he appeared to become increasingly bothered by certain environmental stimuli (e.g., loud or sudden noises, bright lights, crowded, chaotic settings). In addition, she noted that when his level of irritability and agitation were elevated, his tolerance for frustration was significantly reduced, as he tended to become easily distressed when demands were placed on him, when he was asked to wait, and when he was asked to engage in a disliked or boring task. Further, his mother reported that when Jack was hungry (which according to his parents, occurred quite frequently throughout the day since starting the current medications), he seemed to experience more difficulty completing tasks, and he tended to perseverate on gaining access to the item of food that he desired, and became extremely distressed when he had to wait or when he was denied access to the item. Thus, his mother indicated that when these side effects were present, the restaurant routine became much more aversive and challenging for Jack, and consequently, when he experienced greater difficulty in this activity, he was much more likely to display severe levels of problem behavior (e.g., property destruction, tantrums, and aggression) in this context than had been the case prior to starting the current medication combination

Jack's mother identified additional routines that had become more problematic since going on the current medication combination, including "shopping," "grooming routines," and "chores." These activities were identified as the clinical extension contexts, and although no formal data collection occurred in these contexts, following successful implementation of the intervention package in the experimental context, Jack's

family was provided with additional intervention strategies to help them mitigate and more effectively cope with difficulties experienced while completing these activities.

*Participant 2: Ellie*

Ellie was an 11-year-old girl, diagnosed with Autistic Disorder (Full Scale IQ = 42, Stanford-Binet Scales of Intelligence, Fifth Edition), who lived at home with her parents, older brother, and maternal grandparents. She attended a private school that served individuals with developmental disabilities. Ellie demonstrated significant delays in communication skills (both expressive and receptive), and primarily communicated using gestures and a picture point communication system.

*Medication and Side Effects Profile.* Ellie's medication regimen at the time of the study included: valproic acid (500mg/day administered in the morning and evening), and risperidone (2.5mg/day administered in the mid afternoon and evening). Her mother reported that Ellie started the current medication combination within the past several months and the dosages had remained stable throughout the course of the study.

According to her mother's report on the SIAMSE, Ellie experienced several medication side effects including: increased levels of fatigue and lethargy, elevated levels of irritability and agitation, and a marked increase in appetite, leading to significant weight gain (i.e., she gained over 30 pounds in the past 6 months). Ellie's mother reported that the fatigue (as evidenced by appearing physically drowsy, frequently yawning) was most apparent following the administration of the medication, and lasted approximately 2 hours before subsiding. Additionally, she stated that Ellie had much more difficulty waking up in the morning since going on the combination of medication. She also noted that Ellie appeared to be more physically agitated and restless following

administration of the medication, and she seemed more easily irritated by minor annoyances and sensory stimuli. Further, her mother reported that since going on the medication, there had been a marked increase in Ellie's appetite, as she would continuously make requests for food throughout the day, she ate much larger portions during mealtimes, and would frequently search the kitchen for food, even after having recently finished a large meal. Her mother stated that this was a drastic change in her behavior, as in the past Ellie had a more restricted range of foods that she would eat, and she rarely had difficulty when told to "wait" or when denied access to a requested item of food.

*Context Selection.* Ellie's mother participated in the initial assessment, and was administered the SIAMSE. She indicated that "going to the grocery store" had become the most problematic routine for Ellie to complete since starting the current medication combination (i.e., this routine was rated a 5 "much more difficult to complete," on the 5-point Likert scale that measured the level of difficulty of home and community activities); thus, this activity was selected as the experimental context, and became the focus of the intervention. Specifically, she reported that when medication side effects were present, namely, increased levels of fatigue, elevated levels of irritability and agitation, marked increase in appetite, they greatly impeded Ellie's ability to successfully participate the grocery store routine, and ultimately led to an exacerbation of problem behavior that was displayed in this context.

During the follow-up assessment, her mother stated that when Ellie was fatigued, her physical movements were noticeably slower, her responses were much more delayed, she often required greater levels of prompting, and overall it took her much longer to

complete tasks and activities. She noted that Ellie seemed more sensitive to environmental stimuli when she was fatigued, as bright lights, loud noises, and crowded settings seemed to bother her and she became easily distressed over minor annoyances. Moreover, her mother reported that when her level of irritability and agitation were elevated, her tolerance for frustration was substantially reduced, as she often became excessively distressed when presented with task demands or requests, particularly evident in activities that were too long or disliked, or when she had to wait. In addition, her mother reported that when Ellie was hungry (which tended to occur quite frequently throughout the day since starting the medications), she had much greater difficulty completing tasks and activities, as she often became more irritable and extremely distressed when she had to wait or when she was denied access to the item of food that she desired. Thus, her mother indicated that when these side effects were present, the grocery store routine became much more aversive and challenging for Ellie, and consequently, when she experienced greater difficulty in this activity, she was much more likely to display more severe levels of problem behavior (e.g., aggression, property destruction, tantrums, and self-injurious behavior) in this context than had been the case prior to starting the current regimen of medication.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional routines that had become more problematic since going on the current combination of medication, seemingly due to the presence of side effects. These activities were identified as the clinical extension contexts, and included: “brushing teeth” and “bedtime routine.” Although data collection did not occur in these contexts, Ellie’s family was provided with additional mitigation

and coping strategies to address difficulties encountered while completing these activities.

*Participant 3: Neil*

Neil was a 14-year-old boy, diagnosed with Autistic Disorder, Seizure Disorder, and Obsessive Compulsive Disorder (Full Scale IQ = 42, Stanford-Binet Scales of Intelligence, Fifth Edition), who resided at home with his parents and older sister. He attended a private school serving students with developmental disabilities. Neil had extremely limited verbal communication abilities, and used an augmentative communication device as his primary mode of communication.

*Medication and Side Effects Profile.* Neil's mother reported that his medication regimen, which remained unchanged throughout the course of the study, included: quetiapine fumarate (400mg, administered in the morning and evening), paroxetine-controlled release (62.5mg/day, administered in the morning and in the evening), topiramate (250mg/day, administered in the morning and evening), and lorazepam (1mg administered in the evening and used PRN as needed during the day).

According to responses on the SIAMSE, Neil's mother reported that since starting this current combination of medication, she had noted the presence of the following side effects: increased fatigue, elevated levels of irritability/agitation, more frequent episodes of mood instability (e.g., displaying periods of uncontrollable laughing followed by excessive crying spells without apparent provocation), increased appetite, and more frequent headaches. Specifically, she stated that he became noticeably more fatigued (i.e., he appeared physically drowsy, and his motor movements and overall responding to stimuli was delayed) following administration of the medication in the morning, and that



this lasted approximately 1-2 hours; she also noted that his teachers reported observing greater levels of fatigue lasting several hours upon his arrival to school. Additionally, she reported that Neil became increasingly drowsy in the evenings following administration of his medication. Neil's mother noted that he appeared to be more irritable and he became more physically agitated and restless over the course of the day (e.g., frequently pacing around the room, repetitively rocked back and forth in his chair), and he experienced more frequent and rapid changes in mood (e.g., his affect would alternate between suddenly excessive and out of context laughing and uncontrollable crying spells). Additionally, she stated that since going on the medication combination there had been a dramatic increase in his appetite, and he gained at least 15 pounds within the last several months. Furthermore, she reported that Neil appeared to experience more frequent headaches, particularly in the late afternoons/early evenings, as she notes that he seemed to be more sensitive to bright lights (he squinted his eyes, rubbed his head) and more frequently engaged in head-banging behaviors.

*Context Selection.* Neil's mother participated in the initial assessment in which the SIAMSE was administered, and she indicated that multiple community-based routines were difficult for her son to successfully complete. She reported that Neil suffered from severe allergies, and the doctor had recently recommended that he begin weekly treatments of allergy shots. However, she stated that going to the doctor had always been a difficult activity for Neil, and had become even more problematic given that he needed to go on a weekly basis, and appointments were typically scheduled during a time when his mother noted the presence of medication side effects. Thus, she identified "medical appointments" as the experimental context, and this activity became the focus of the

intervention (i.e., this routine was rated a 5 “much more difficult to complete,” on the 5-point Likert scale that measured the level of difficulty of home and community activities). Specifically, his mother stated that when medication side effects were present, namely increased fatigue, elevated irritability/agitation, greater levels of irritability/agitation, more frequent changes in mood, increased appetite, and headaches, they greatly interfered with Neil’s ability to successfully complete this community-based routine, and ultimately resulted in an exacerbation of problem behavior that was displayed in the context.

During follow-up assessment, his mother explained that when Neil was fatigued, he tended to experience greater difficulty completing common tasks and activities, as he physically moved at a much slower pace, his responses were substantially delayed, and it seemed to take him much longer to complete even simple routines. She also noted that when her son was fatigued and when he appeared to be more irritable and agitated, his tolerance for frustration was substantially reduced, as he more frequently became excessively distressed when presented with task demands, requests, or when he had to wait. Additionally, she reported that when Neil had a headache, he was much more sensitive to certain environmental stimuli (e.g., bright lights, loud noises, strong scents), and seemed to have a great deal of difficulty concentrating (maintaining focus/attention) on tasks. When Neil was hungry (which occurred more frequently since starting the current medications), his mother explained that he appeared to experience greater difficulty completing tasks, as he often became much more irritable and extremely distressed when he had to wait or when he was denied access to the item of food that he desired. Thus, his mother indicated that when these side effects were present, they tended

to make the medical appointment routine much more aversive and challenging for Neil, and consequently, when he experienced greater difficulty in this activity, he was much more likely to display more severe levels of problem behavior (e.g., aggression, property destruction, tantrums, and self-injurious behavior) in this context. Importantly, she noted that the majority of appointments had to be terminated before the shot could be administered, due to the significantly interfering behaviors he exhibited.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional routines that had become more problematic since going on the current combination of medication, seemingly due to the presence of side effects. These activities were identified as the clinical extension contexts, and included: “transitioning to and from the bus” and “household chores.” Although data collection did not occur in these contexts, Neil’s family was provided with additional mitigation and coping strategies to address difficulties encountered while completing these activities.

#### *Baseline Observations*

As noted previously, baseline was divided into two components, an initial validation phase and an extended baseline phase. Following the completion of five validation sessions, each family entered the extended baseline phase. Throughout both baseline components, direct observations were conducted by multiple informants (i.e., the primary parent rater, a second caregiver, the primary investigator, and a second researcher) to confirm the presence of problem behavior and to assess ancillary dependent variables (i.e., primary parent rater and second caregiver rater only). The same observation and data collection procedures were utilized in both the initial validation

phase as well as in the extended baseline phase, as described in Study 1. For each family, one parent was identified as the primary parent rater, and was responsible for the ongoing data collection throughout the baseline and intervention conditions. A second caregiver conducted observations and collected data in the experimental contexts on multiple occasions during both components of baseline, as well as in the intervention condition. The investigator (the first author) conducted multiple direct observations and collected data in the experimental contexts of all the participants to confirm that the specified activity was associated with the occurrence of problem behavior, and that a low percentage of transition steps were completed. On several occasions throughout both components of baseline and during intervention, a second observer, who was blind to the hypotheses of the study, also conducted direct observations and collected data in the experimental context for all participants.

A task analysis was developed for the experimental context identified for each participant, and was used to measure each child's completion of the problematic routine. Recall that the experimental context identified for Jack was "eating in restaurants," and the sequence of steps involved in this task included: (1) Jack entered the restaurant and ordered his food; (2) Jack sat down and waited for his food to be brought to the table; (3) Jack ate his food; (4) Jack exited the restaurant upon completion of the meal. For Ellie, "going to the grocery store" was identified as the priority problem context, and the sequence of activity steps was defined as follows: (1) Ellie walked into the grocery store and retrieved a shopping cart; (2) Ellie obtained three items that were on her grocery list, and placed them into the shopping cart; (3) Ellie waited on line and paid the cashier; (4) Ellie exited the store and put the groceries in the car. For Neil the experimental context

was weekly “doctor appointments,” and the sequence of steps involved in this routine was defined as follows: (1) Neil walked into the doctor’s office within 2 minutes of his mother delivering the verbal discriminative stimulus “Let’s go into the doctor’s office;” (2) Neil sat on the examination table and allowed the doctor to administer the allergy shot and briefly examine him; (3) Neil waited in the examination room (for at least 20 minutes) until the doctor returned to re-examine him (to ensure he did not have an adverse reaction to the shot); (4) Upon receiving approval from the doctor, Neil walked out of the office.

To ensure the safety of the child and the parent, sessions were terminated contingent upon the demonstration of problem behavior defined as either: (1) the occurrence of a single instance of “untolerated” problem behavior, namely, aggression (e.g., hitting, dropping to the floor, kicking) or self-injurious behavior (e.g., biting hand, hitting head), or more than 5 seconds of screaming (Carr & Carlson, 1993), or (2) three instances of “tolerated” problem behavior, defined as brief episodes (i.e., less than 5 seconds) of screaming, verbal protests, and/or stomping feet on the floor. Tolerated problem behavior was seen as less serious by the parents and, thus, up to three instances of such behavior were allowed prior to the termination of the session.

#### *Response Recording*

Data collection procedures for this study were similar to those described in Study 1. Multiple informants collected data to measure several primary dependent variables including: (a) percentage of task steps completed, (b) latency to session termination due to the occurrence of problem behavior or successful completion of the community-based activity, and (c) the reason for session termination. As in Study 1, the primary parent rater

and a second caregiver (on multiple occasions) collected additional data to measure several ancillary dependent variables that included: (a) recordings (i.e., binary yes/no measure) that indicated the presence or absence of medication side effects in the experimental context, (b) ratings of the level of intensity of the side effects that were present (using a 5-point Likert scale), (c) recordings (i.e., binary yes/no measure) indicating the presence or absence of difficulty experienced while completing the community-based activity, (d) ratings of the level of difficulty that was experienced during completion of the experimental context (using a 5-point Likert scale), and (e) ratings of the overall level of severity of problem behavior displayed by the child in the activity (using a 5-point Likert scale).

*Development of the Intervention and Training of the Intervention Agent*

As delineated in Study 1, the purpose of this component was to use assessment information about each of the problematic community-based routines to develop a uniquely tailored intervention package comprised of evidence-based practices to mitigate various aspects of the problematic contexts, and to teach the child coping skills so that he/she could more effectively deal with the side effects, and ultimately be able to successfully complete the identified difficult routines. Once the intervention package was implemented in the experimental context, the investigator taught the families several additional strategies which they implemented in the clinical extension contexts. As noted previously, the decision processes for initiating, continuing, and terminating the intervention in the experimental context are outlined in Appendix E. The rationale for implementing each component of the intervention package for participants in all three studies is shown in Appendix D.

Each family directly participated in the development of the unique intervention package utilizing a problem solving approach, as outlined in Appendix C. Although each package followed a generic model using mitigation and coping procedures, the precise nature of each strategy was determined by the specific properties of each context, including the characteristics of the various side effects that were present. Interventions were implemented that the families considered user-friendly and feasible, following procedures using the goodness-of-fit assessment described in Appendix H (Albin et al., 1996).

*Participant 1: Jack*

According to data obtained from the assessment measures and baseline observations, eating in restaurants with the family had become more difficult for Jack to complete since going on the current medication regimen. Specifically, his mother stated that when side effects were present, particularly when he experienced elevated levels of fatigue and increased haziness/difficulty concentrating, and increased appetite, they appeared to make this community-based routine more aversive, and, in turn, Jack tended to display more severe levels of problem behavior when attempting to complete this activity. Thus, to address the difficulties he experienced during this routine, an intervention package comprised of mitigation and coping strategies was created.

*Mitigation Strategies for Eating in Restaurants.* Research has suggested that the lack of predictability associated with certain activities and routines can serve to evoke problem behavior displayed by individuals with autism (Flannery & Horner, 1994). A *visual schedule* depicting upcoming events and the steps involved in the sequence of an activity has been found to be effective in reducing problem behavior, as such a schedule

reduces the unpredictability associated with activities and transitions because the child is provided with information about the upcoming sequence of events (Mesibov et al., 2002). Further, children with autism spectrum disorders are often described as being “visual learners,” and studies have demonstrated the beneficial effects of utilizing visual schedules with this population (McClannahan & Krantz, 1999). Therefore, to enhance the predictability of the restaurant routine for Jack, we constructed a portable visual schedule with pictures and printed words that depicted the sequence of steps comprising this activity. To further enhance the predictability of this activity, a large calendar was hung up in the kitchen, and his mother posted pictures of the various community activities that the family would be completing for the week. Each morning, she would review the day’s activities with Jack to ensure that he was *provided with advanced preparation* and to reduce any anxiety that may be caused by a lack of predictability.

Waiting for an activity to begin has been found to correlate with increased problem behavior displayed by individuals with developmental disabilities (McGill, Terr, Rye & Hughs, 2005; Horner, 1997). Jack’s mother reported that when his medication side effects were present, increased fatigue and increased appetite in particular, he had a much more difficult time when expected to “wait.” She explained that typically during the mealtime restaurant routine, Jack would be expected to sit with his brother in a booth and wait for the food to be brought to the table. However, since going on the current medications, it became much harder for him to sit and wait, and problem behavior was much more likely to be displayed. Research has shown that *embedding preferred items into difficult or disliked activities* can effectively reduce problem behavior (Blair et al., 1999). Therefore, we decided to include embedding a preferred activity into the routine



while he waited. Specifically, we asked Jack to choose a preferred item (either a handheld video game, or drawing in his favorite notebook) to use while he waited for his food to arrive. Jack was shown picture icons of both items and made his choice. A preference assessment checklist (Matson et al., 1999) was conducted prior to the development of the intervention package, to identify several potent reinforcers and highly preferred items that could be incorporated into various components of the package.

*Coping Strategies for Eating in Restaurants.* Research has demonstrated that certain environmental features may be associated with increased levels of problem behavior (Kern, Sokol, & Dunlap, 2006), and studies have suggested that problem behavior evoked by noise may function as a means of escaping or avoiding the aversive situation (McCord, Iwata, Galensky, Ellingson, & Thomson, 2001; O'Reilly, Lacey, & Lancioni, 2001). According to Jack's mother, he appeared much more sensitive to loud noises when he was experiencing elevated levels of fatigue and increased haziness/difficulty concentrating following medication administration. Replacing problem behavior with *functionally equivalent communication skills* has been found to reduce problem behavior (Carr & Durand, 1985). Thus, in order to help him effectively deal with noisy environments when experiencing side effects, Jack was taught a coping strategy, namely, to use a visual card to indicate the need to *take a "break."* Essentially, he was taught to use this functionally equivalent and more appropriate means to communicate his need for a break. Specifically, when the restaurant became noisy, or when his family members noticed that he was becoming noticeably distressed or irritable, Jack was prompted to point to the break card that was placed on the table in front of him. Upon requesting the break, his mother (or another family member) would provide him

with the choice of either putting on his headphones to listen to music for several minutes or going outside for a brief walk. Essentially, both options provided Jack with a means of more appropriately escaping the seemingly aversive environment. A *visual choice board* was shown to Jack to further assist him in making the choice of a break activity. As noted previously, research has demonstrated that including *opportunities for choice making* in an intervention package can contribute to the reduction of problem behavior (Shogren et al., 2004).

*Clinical Extension.* Jack's mother also identified two additional contexts that had become more difficult to successfully complete since going on the current medication, due to the presence of medication side effects. As in Study 1, no experimental demonstration was included in this portion of the study. Additional mitigation and coping skills strategies were developed and implemented to address problem behavior in the following clinical extension contexts: (a) "shopping," and (b) "household chores." As noted earlier, the use of visual supports have been found to reduce problem behavior in individuals with autism (Mesibov, et al., 2002). Thus, to enhance predictability associated with the shopping in the community routine, we provided Jack with a visual task board that was comprised of picture icons representing the various locations involved in the day's shopping trip. As he completed each activity (e.g., going to the bank with his mother; picking up dry cleaning; dropping off younger brother at karate class; etc.), he was taught to remove the icon representing the particular task, and place it in an envelope attached to the back of the board. The final picture on the task board depicted a preferred item or activity that he could access upon returning home. In addition, his mother noticed that his hunger had substantially increased since going on medication, and this appeared

to negatively impact the shopping trips in the community, as Jack frequently seemed hungry, and would attempt to gain access to food using inappropriate means. He also had greater difficulty tolerating being told “no,” or to “wait,” and was more likely to engage in problem behavior. Thus, we used *a neutralizing routine*, namely, providing Jack with a meal or substantial snack prior to the start of the shopping trip. We also provided a small snack (items chosen by Jack prior to the activity) for him to bring in the car that he could have access to when he was hungry. Neutralizing routines have been found to be effective in addressing problem behavior displayed by individuals with developmental disabilities when introduced between the presence of a setting event such as hunger, and the presentation of an aversive task (Horner, Day & Day, 1997).

Studies have demonstrated the effectiveness of using visual supports such as activity schedules and visual representations of time (e.g., a timer) in reducing problem behavior, as these strategies enhance predictability associated with difficult activities (Mesibov et al., 2002; Dettmer et al., 2000). Given the positive response to the visual schedule used in the shopping and restaurant routines, we created a visual schedule for Jack to use in the household chores routine. This schedule was composed of picture icons representing the sequence of steps comprising the household chores routine, and was constructed so that it was portable and was used in the same manner as the other schedules that he had learned to utilize.

*Participant 2: Ellie*

As previously noted, community integration of people with developmental disabilities is often impeded by the presence of severe problem behavior. Research has shown that multicomponent interventions implemented in problematic community-based

contexts effectively reduce problem behavior displayed by individuals with developmental disabilities, and often result in increased family participation in meaningful activities and routines in the community (Carr & Carlson, 1993; Feldman, Condillac, Tough, Hunt, & Griffiths, 2002; Lucyshyn, et al., 2007). Recall that “going to the grocery store” was identified as the experimental context for Ellie. Specifically, her mother stated that when side effects were present, particularly when she experienced elevated levels of fatigue and increased appetite, they appeared to make this community-based activity much more difficult for her, and, in turn, Ellie displayed more severe levels of problem behavior when attempting to complete this routine. Thus, to address the difficulties she experienced during this community routine, an intervention package comprised of mitigation and coping strategies was created.

*Mitigation Strategies for the Grocery Store Routine.* Research has demonstrated that the presence of an underlying health condition associated with pain or discomfort (e.g., allergies, sleep deprivation, gastrointestinal disorders; menstrual discomfort) may contribute to increased problem behavior displayed by individuals with developmental disabilities (Carr et al., 2003; Kennedy & Meyer, 1996; O’Reilly, 1995). Investigators have suggested that the onset of discomfort experienced by individuals such as fatigue, gastrointestinal bloating, heartburn, and cramping may act as a motivating operation; thus, establishing certain stimuli or events as aversive or increasing their noxious properties, and, in turn, evoking higher rates of negatively reinforced behaviors (Kennedy & Becker, 2006; Kennedy & Thompson, 2000). According to her mother, Ellie experienced greater levels of fatigue following administration of her medication, which often correlated with the time when they attempted to go to the grocery store.

Consequently, when fatigued, this activity became increasingly more difficult for her, as she appeared to experience greater levels of overall irritability and discomfort, as well as a reduced tolerance for environmental stimuli including loud noises and crowded settings. Thus, to address some of the difficulty experienced in the grocery store routine, we *modified several aspects of this activity*. Given the pattern of fatigue that was often observed upon taking her medication, we altered the time that this activity was scheduled, so that it occurred during times when she was less likely to experience fatigue caused by her medication. As a result of this change in the scheduling of this activity, it was presented during times when the grocery store was less likely to be crowded and noisy, further reducing some of the aversive qualities of this routine.

Research has shown that a *visual representation of routines* is associated with decreased levels of problem behavior displayed by individuals with autism (Mesibov et al., 2002). Further, the use of visual supports, including visual schedules has been found to increase predictability, thereby making the activity or routine in which it is used easier for the child to complete. Therefore, to enhance the predictability of the grocery store routine, a visual schedule depicting the steps involved in this routine was constructed. Ellie was provided with a portable clipboard with photographs representing each step involved in the sequence of this routine. Upon completing each step, Ellie was taught to remove the corresponding picture and place it into an envelope attached to the back of the board. This visual schedule closely resembled the schedules that Ellie regularly used throughout the day in school, thus she was already familiar with how to use this strategy.

According to the behavioral literature, hunger has been found to function as a setting event for problem behavior (Wacker, Harding, Cooper, Derby, Peck, Asmus, et

al., 1996). The use of *neutralizing routines* has been shown to reduce problem behavior when introduced between the presence of a setting event (e.g., hunger), and the presentation of an aversive discriminative stimulus such as a task-related demand (e.g., “let’s finish getting our groceries”). Given the increased likelihood that Ellie would experience even greater levels of hunger when in the presence of such a vast array of food items in the grocery store, we introduced a neutralizing routine (eating) by providing Ellie with a complete meal (either lunch or dinner) just prior to going to the grocery store, as a way of mitigating her hunger, and thereby reducing the likelihood that she would display problem behavior while participating in this activity. In addition, Ellie was provided with *noncontingent access to small food items (snacks)* throughout the grocery store routine, to further address any hunger she may experience, and to reduce the likelihood of engaging in problem behavior related to wanting to gain access to food items in the store.

*Coping Strategies for the Grocery Store Routine.* Studies have demonstrated that being denied access to a desired tangible item increases the likelihood that problem behavior will be displayed (Vollmer, Borrero, Wright, Van Camp, & Lalli, 2001). Researchers have suggested that being denied access to an item that is desired is aversive to the child and thus evokes problem behavior that functions to gain access to that tangible item (Durand & Crimmins, 1988). As noted previously, Ellie’s mother reported a considerable increase in her daughter’s appetite since starting the most current combination of medication, and she appeared to experience increased hunger throughout the day. Further, she noted that Ellie more frequently made requests for food, and when she was denied access to food items or when she was told that she had to “wait” before

gaining access to an item, she became increasingly distressed and was subsequently very likely to display problem behavior. Thus, going to the grocery store became more problematic for the family when Ellie was hungry, as she more frequently attempted to gain access to food items while in the store, and displayed tantrum behavior and property destruction when she was told to “wait” or when she was denied access. Research has demonstrated that the *use of relaxation techniques* is associated with reduced levels of agitation and problem behavior in individuals with developmental disabilities (Mullins & Christian, 2001). To address the difficulty associated with being denied access to desired items or told to wait when experiencing hunger, we taught Ellie several relaxation techniques to help her more effectively cope with distress that was often associated with this routine. Specifically, Ellie was taught a simple *deep breathing exercise and a brief progressive muscle relaxation technique* that she could engage in when she became distressed if she was denied access to something she wanted, or when she had to wait in order to gain access to an item. Similar techniques had been introduced to Ellie by her teachers in school, and were found to be effective in reducing her level of distress, and preventing an escalation of problem behavior. We taught these techniques to her parents so that they could model and prompt her to use them when they noticed that she was becoming irritable or agitated.

Research has shown that *teaching functionally equivalent communication skills* can be associated with decreases in problem behavior (Carr & Durand, 1985). According to her mother, Ellie had a tendency to take food off of the supermarket shelves and eat without being given permission, and she stated that this made the grocery store routine difficult, particularly when side effects such as increased hunger and elevated

irritability/agitation were present. Therefore, to minimize the likelihood that she would inappropriately attempt to gain access to food in the store, we taught Ellie to request an item using her communication book rather than by aggression or by grabbing it without permission. We created a picture icon representing “I want” and placed it in the front section of her communication book so that it could be easily accessed, and when she grabbed an item, she was prompted to first point to the picture icon then to the item to make the request. Her mother provided behavior specific praise (e.g., “Nice job asking for the cookies, Ellie!”) to reinforce the appropriate request, and she was given a portion of the item when possible. If Ellie requested an item that she was unable to immediately access, her mother provided her with a choice between two highly preferred snack items that were brought from home which she was permitted to eat while they completed the routine.

*Clinical Extension.* Ellie’s mother identified three additional contexts that had become more difficult for her daughter to complete due to the presence of side effects including: (a) completing household chores, (b) brushing teeth, and (c) the bedtime routine. Additional mitigation and coping strategies were developed and implemented to reduce problem behavior in these clinical extension contexts.

Tasks and activities that are too long and that are difficult have been shown to be associated with an increase in problem behavior displayed by individuals with developmental disabilities (Sweeney & LeBlanc, 1995). Thus, modifications were made to each of the clinical extension contexts to reduce the level of difficulty that was experienced when side effects were present. As noted previously, research has demonstrated that the use of visual representations of the sequence of steps comprising



routines increases predictability and is associated with reductions in problem behavior (Mesibov et al., 2002). Thus, a visual schedule depicting the various steps involved in each routine was implemented in both the household chores activity and in the brushing teeth routine to enhance predictability and subsequently reduce some of the difficulty associated with these activities. Research has also shown that verbal warnings often enhance predictability and are associated with decreased levels of problem behavior (Mace, et al., 1998). Therefore, to mitigate the impact of these difficult contexts, parents were instructed to provide verbal warnings prior to the onset of these three activities. For example, Ellie's mother delivered a verbal warning (e.g., "Ellie, 1 minute until bedtime") at 3 minute and 1 minute intervals prior to the start of the difficult activity. The advanced warning made the change in activity more predictable for Ellie. Additionally, Ellie was presented with a visual representation (i.e., a picture icon) of a reward that would be given upon successful completion of the household chores and the brushing teeth routines. Thus, the picture served as a discriminative stimulus for displaying appropriate behavior and completing the steps of the routine.

Studies have shown that the prevalence of sleep disturbances experienced by children with developmental disabilities is higher than in typically developing individuals (Richdale, Gavidia-Payned, Francis, & Cotton, 2000). Further, sleep-related difficulties have been found to be associated with increased levels of problem behavior ((Durand, Gernert-Dott, & Mapstone, 1996; Kennedy & Meyer, 1996; Wiggs & Stores, 1996). Several behavioral procedures have been found to be effective in reducing disruptive sleep patterns in children with developmental disabilities, including the *use of positive bedtime routines* (Christodulu & Durand, 2004). We developed a specific routine that

was consistently implemented each night to increase the predictability of bedtime. Every evening at 9:30 pm, Ellie's mother delivered a verbal warning alerting her that it was time to get ready for bed. She was prompted to use the bathroom and to change into her pajamas. Ellie's mother provided assistance as needed, and accompanied her to her bedroom. Once she got into her bed, her mother took out a family photo album (a preferred item) and looked through the pictures with her as she told her a story about one of the events depicted in the album. According to a preference assessment conducted with her mother, looking at photographs and listening to stories about past family vacations and events was highly reinforcing, thus we incorporated this into the intervention package to increase the likelihood of compliance during this difficult routine. After finishing the story, her mother kissed her goodnight, turned off the light, and closed the door. In addition to establishing a consistent bedtime routine, Ellie's parents also redirected her back to her room during the night if she woke up; they physically escorted her back to her bed and did not verbally engage with her.

*Participant 3: Neil*

Research has shown that medical appointments and medical settings in general are often associated with problem behavior displayed by individuals with developmental disabilities (Carlson, 2000). Recall that "going on weekly doctor appointments" was identified as the experimental context for Neil. Specifically, his mother stated that when side effects were present, particularly when he experienced elevated levels of fatigue, elevated irritability and agitation, and increased appetite, they appeared to make this community-based activity much more difficult for him, and, in turn, Neil displayed more severe levels of problem behavior. Thus, to address the difficulties experienced during

this community routine, an intervention package comprised of mitigation and coping strategies was created.

*Mitigation Strategies for Medical Appointments.* *Social stories* have been found to be an effective strategy to enhance predictability about upcoming events or difficult activities, and studies have shown that the use of these stories is associated with decreased problem behavior displayed by individuals with autism spectrum disorders (Gray & Garand, 1993; Sansosti, Powell-Smith, & Kincaid, 2004). Thus, we included social stories as a mitigation strategy to address difficulties associated with medical appointments. We created and implemented a simple social story to increase the predictability of the various steps involved in the weekly medical appointments. The story consisted of pictures depicting the sequence of steps of the appointment including the arrival at the office, meeting with the doctor and receiving the allergy shot, sitting in the examination room waiting for the doctor to reexamine him, walking out of the office. In addition, we included pictures of Neil displaying appropriate behavior (e.g., calmly sitting on the examination table with his hands in his lap while the doctor administers the allergy shot), as well as the positive response of his parents to his appropriate behavior. His parents reviewed the story with him two days prior to the appointment when he was calm to ensure that it was associated with positive experiences and not perceived as a task demand.

The *use of a visual representation of time (i.e., a timer)* has been found to enhance predictability and consequently, reduce problem behavior (Dettmer et al., 2000). Therefore, a visual timer was included in the intervention package to increase predictability and reduce some of the difficulty Neil experienced during this community-

based context. Specifically, the timer was used during the portion of the activity when it was necessary for Neil to remain in the exam room and wait for the doctor to reexamine him after receiving the shot, to ensure that he did not experience an adverse reaction. Following the administration of the allergy shot, his mother set the timer for 20 minutes and periodically provided verbal reminders alerting him to the amount of time remaining until the step in the routine ended (e.g., “Only 3 more minutes until wait-time is all done”).

*Neutralizing routines* have been found to effectively reduce problem behavior that is associated with waiting (Horner et al., 1997). Therefore, while waiting to be reexamined by the doctor, a neutralizing routine, namely, engaging in a preferred activity, was included as a mitigation strategy. Specifically, Neil was given the opportunity to choose a DVD (a highly preferred activity) to view on a portable DVD player while he waited without engaging in problem behavior. In addition, Neil was able to lie down on the exam table during the “wait time” and rest; no demands were placed on him during this time to further reduce the likelihood that he did not engage in problem behavior.

*Coping Strategies for Medical Appointments.* Providing *opportunities for making choices* in difficult or disliked activities is a strategy that has been shown to reduce problem behavior in individuals with developmental disabilities (Shogren et al., 2004). Thus, to reduce the aversive quality of the doctor appointment routine, Neil was given the opportunity to choose the DVD he wanted to watch during the wait-time portion of the activity. In addition, he was provided with a choice of a highly preferred activity he could engage in upon successful completion of the activity.

Research has demonstrated that teaching individuals with developmental disabilities to use *relaxation strategies* can effectively reduce agitation, anxiety, and problem behavior (Mullins & Christian, 2001). According to his mother, medical appointments had typically caused Neil a great deal of anxiety; however, since going on the current medication regimen, he appeared to experience increased levels of anxiety and irritability that greatly interfered with this activity. Therefore, we taught Neil relaxation techniques including a *deep breathing exercise and a simple progressive muscle relaxation technique* (Cautela & Groden, 1978) to help him more effectively cope with distressing situations. These strategies were also taught to his parents and his home-based therapists so that they could model and prompt him to use these techniques upon noticing increased levels of anxiety. The relaxation strategies were practiced with Neil approximately 4-5 days per week during brief instructional sessions.

*Clinical Extension.* Neil's mother identified two additional contexts that had become more difficult for her son to complete due to the presence of side effects including: (a) household chores, and (b) transitions. Additional mitigation and coping strategies were developed to reduce problem behavior in these clinical extension contexts. Given Neil's positive response to the social story we implemented in the medical appointment routine, we created additional stories utilizing the same format for the household chores routine. Photographs depicting the sequence of steps involved in this routine were included in the simple story that was written to enhance predictability and to prepare Neil for this difficult and disliked activity. The story was reviewed with Neil on days when he was expected to complete his household chores (approximately 4-5 days per week), and was presented when he was in a relaxed state.

As noted previously, transitions between locations have been found to be associated with a lack of predictability that is involved in evoking increased levels of problem behavior in individuals with developmental disabilities (Flannery & Horner, 1994; Schmit et al., 2000). Therefore, to enhance the predictability of Neil's transitions between settings, we created and implemented a visual schedule of the settings to which he would be transitioning to. He was presented with a portable board that had pictures representing locations that he would be traveling, and as he completed each step of the transition, he was prompted to remove the corresponding picture and place it in the "finished" envelope that was pasted to the back of the board. Additionally, a picture representing a highly preferred activity that Neil was permitted to engage in upon arriving home was placed at the bottom of the schedule to remind him of the reward he would receive upon successfully completing the transition.

Once the intervention package was developed, the investigator trained the intervention agent (for Jack, his mother; for Ellie, her mother; for Neil, his mother and home-based therapist) to carry out the intervention package. The investigator provided verbal explanation of the procedures and then modeled the use of the strategies with the child for a minimum of two sessions. A written description of the intervention components was given to each intervention agent to use, as needed, as an additional form of visual support. The intervention agent implemented the multicomponent intervention package with verbal feedback from the investigator for one session. Verbal feedback was faded, as the intervention agent implemented the intervention package independently for a minimum of two sessions.

### *Intervention Fidelity*

As described in Study 1, an intervention fidelity checklist, based on the specific intervention components for each participant, was developed to evaluate intervention integrity for the experimental context (see Appendix I, Intervention Integrity Checklist, displaying the intervention components designed for priority contexts for all three studies). In 60% of the baseline sessions, and 55% of the intervention sessions for Jack, in 63% of the baseline sessions and 82% of the intervention sessions for Ellie, and in 55% of the baseline sessions and 57% of the intervention sessions for Neil, the primary parent rater and the investigator recorded whether each intervention component was implemented. That is, the primary parent rater and the investigator completed the treatment fidelity checklist by recording a checkmark whenever a specific component of the multicomponent intervention package was implemented by the parent in the experimental context.

### *Interrater Reliability*

Utilizing the same procedures as in Study 1, multiple informants collected reliability data on the independent and dependent variables in the experimental contexts. A binary reliability index was used to assess agreement between the primary parent rater and the investigator on intervention fidelity, and on the primary dependent variables including: the percentage of context steps completed, latency to session termination, and the reason for session termination. For each session, reliability was scored as either perfect agreement or no agreement. Agreement was defined as both observers recording the implementation of the intervention components, the same number of task steps that were completed in the context that they observed, latency measures that were within 5

seconds of one another, and agreement on the reason for session termination (i.e., due to the occurrence of problem behavior or the successful completion of the activity).

The primary parent rater and the second caregiver rater collected reliability data, in the experimental context, on the primary dependent variables, as well as on ancillary dependent variables including: the presence of medication side effects, ratings of the level of intensity of the side effects, the presence of difficulty experienced in the problematic activity/routine, ratings of the level of difficulty experienced, and ratings of the overall level of problem behavior severity displayed by the child in the experimental context. A binary reliability index was used to assess agreement on all of the dependent variables; thus, for each session, reliability was scored as either perfect agreement or no agreement. The same parameters, as outlined in Study 1, were used to define agreement for the primary dependent variables.

A second researcher, blind to the hypotheses of the study, was present to observe and collect data in the experimental context on multiple occasions. A binary reliability index was used to assess the agreement between data recorded by the investigator and the second researcher on the percentage of task steps completed, latency to session termination, and the reason for session termination (due to problematic behavior or successful completion). For each session, reliability was scored as either perfect agreement or no agreement, and agreement was defined using the same parameters that were described previously for these primary dependent variables.

*Participant 1: Jack*

For the experimental context, the primary parent rater and a second caregiver independently (but concurrently) completed reliability checks for 60% of the baseline



sessions and 55% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 60% of the baseline sessions and 60% of the intervention sessions. Agreement on the percentage of task steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on the presence/absence of side effects, presence/absence of difficulty in the experimental context, and the level of difficulty ratings was noted in 100% of both the baseline and intervention sessions. Agreement on the ratings of the level of intensity of side effects that were present was noted in 100% of the baseline sessions and 92% of the intervention sessions. Agreement on the ratings of the level of problem behavior severity was noted in 100% of the baseline sessions and 83% of the intervention sessions,

Reliability checks were also independently (but concurrently) completed by the investigator and the second (blind) researcher for 40% of the baseline sessions and 50% of the intervention sessions. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

*Participant 2: Ellie*

For the experimental context, two observers (the primary parent rater and a second caregiver) independently (but concurrently) completed reliability checks for 63% of the baseline sessions and 82% of the intervention sessions. Agreement on intervention

fidelity, the percentage of context steps completed, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 100% of the baseline sessions and 93% of intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 63% of the baseline sessions, and 76% of the intervention sessions. Agreement on the percentage of task steps completed, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 80% of the baseline sessions, and 100% of the intervention sessions. Agreement on the ancillary dependent variables including the presence/absence of side effects, presence/absence of difficulty in the experimental context, and the level of problem behavior severity ratings was noted in 100% of both the baseline and intervention sessions. Agreement on the ratings of the level of intensity of side effects that were present was noted for 100% of the baseline sessions and 85% of the intervention sessions. For 100% of the baseline sessions and 93% of the intervention sessions, agreement on the ratings of the level of difficulty was noted.

For 50% of the baseline sessions and 53% of the intervention sessions, reliability checks were independently (but concurrently) completed by the investigator and the second (blind) researcher. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

*Participant 3: Neil*

For the experimental context, the primary parent rater and the investigator independently (but concurrently) completed reliability checks for 55% of the baseline sessions and 57% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 83% of the baseline sessions and 100% of intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 73% of the baseline sessions and 71% of the intervention sessions. Agreement on the percentage of task steps completed, latency to session termination, and reason for session termination was noted in 100% of the baseline and intervention sessions. Further, agreement on the presence/absence of side effects, ratings of the level of intensity of side effects, and the presence/absence of difficulty experienced in the experimental context was noted in 100% of the baseline and intervention sessions. Agreement on the ratings of the level of difficulty that was experienced in the experimental context was noted in 75% of the baseline sessions and 100% of the intervention sessions. Agreement on ratings of the level of problem behavior severity was noted in 100% of the baseline sessions and 90% of the intervention sessions,

Reliability checks were also independently (but concurrently) completed by the investigator and the second (blind) researcher for 45% of the baseline sessions, and 43% of the intervention sessions. Agreement on the percentage of context steps completed,

latency to session termination, and reason for session termination was noted in 100% of both the baseline and the intervention sessions.

## Results

### *Intervention Fidelity*

In baseline, a mean of 0% of the intervention components were implemented by each parent in their respective experimental contexts. During intervention, a mean of 100% of the intervention components were implemented by each parent in the experimental contexts.

### *Percentage of Steps Completed*

The percentage of community-based routine steps completed for each participant is displayed in Figure 5. In baseline, Jack completed a mean of 20% of the steps that comprised the “restaurant” routine. During intervention, however, he completed a mean of 100% of the steps in 15 out of 20 sessions, and a mean of 65% of the steps in the remaining five sessions. Ellie, in baseline, completed a mean of 6.25% of the steps that constituted the “grocery store” routine. During intervention, she completed a mean of 100% of the steps in 11 out of 17 sessions, and a mean of 67% of the steps in the remaining six sessions. In baseline, Neil completed a mean of 18.2% of the steps that comprised the “weekly medical appointments” routine. During intervention, however, he completed a mean of 100% of the steps in 8 out of 14 sessions, and a mean of 67% in the remaining six sessions.

### *Latency to Problem Behavior*

Figure 6 displays data on the amount of time that elapsed before the session was terminated (due to either the occurrence of problem behavior or the successful

completion of the activity) for the three participants. For Jack, the mean latency to problem behavior displayed during the restaurant routine in baseline was 4 min, 40 s. The mean latency to problem behavior during intervention was 12 min, 17 s in the five sessions that were terminated; however, the mean latency to successful completion of the restaurant routine (15 out of 20 sessions) was 20 min, 10 s. For Ellie, the mean latency to problem behavior displayed during the grocery store routine in baseline was 3 min, 23 s. During intervention, mean latency to problem behavior was 11 min, 31 s in the six sessions that were terminated, and mean latency to successful completion of the grocery store routine (11 out of 17 sessions) was 15 min, 6 s. In baseline, for Neil, the mean latency to problem behavior demonstrated during the medical appointment routine was 5 min, 23 s. The mean latency to problem behavior during intervention was 22 min, 14 s in the six sessions that were terminated due to problem behavior, and mean latency to successful completion of the medical appointment routine (8 out of 14 sessions) was 29 min, 21 s.

#### *Reason for Session Termination*

Figure 6 shows that sessions could be terminated due to the presence of untolerated problem behavior (indicated by solid black bars), tolerated problem behavior (indicated by solid pink bars), or successful completion of the problematic community-based activity/routine in the absence of problem behavior (indicated by open bars). For each participant in baseline, all sessions were terminated due to the presence of untolerated and tolerated problem behavior (i.e., none of the baseline sessions were successfully completed). During intervention for Jack, 1 out of 20 sessions was terminated due to untolerated problem behavior (as indicated by solid black bars), and 4

out of 20 sessions were terminated due to tolerated problem behavior (as indicated by pink bars); however, the remaining 15 sessions were successfully completed. For Ellie, in intervention, 1 out of 17 sessions was terminated due to intolerated problem behavior, and 5 out of 17 sessions were terminated due to tolerated problem behavior; the remaining 11 sessions were successfully completed. For Neil, 2 out of 14 intervention sessions were terminated due to intolerated problem behavior, and 4 out of 17 sessions were terminated due to tolerated problem behavior; the remaining eight sessions were successfully completed.

#### *Presence or Absence of Medication Side Effects*

For each participant, a binary (yes/no) measure was used to document the presence (or absence) of the medication side effects experienced in their respective community-based experimental context. The primary parent raters for all three participants indicated that medication side effects were in fact present (at elevated levels) in 100% of the sessions throughout baseline and intervention, as evidenced by data presented in Figure 7 which displays ratings of the level of side effect intensity for each participant in Study 2.

#### *Level of Intensity of Medication Side Effects*

As previously noted, parents were asked to rate the level of intensity of the medication side effects that were present in the experimental context, using a 5-point Likert scale (values ranging from *mild to severe*). Figure 7 displays ratings (provided by primary parent raters) of the level of intensity of the various side effects that were experienced by each participant in their problematic community-based routines. For all three participants, side effect intensity ratings were in the *severe* range (i.e., the level of

intensity was rated a 4 or 5 on the 5-point Likert scale) for all sessions throughout the baseline and intervention phases. The mean rating of the level of intensity of side effects experienced by Jack was 4.2 in baseline and 4.5 during intervention. For Ellie, the mean rating of the level of intensity of medication side effects was 4.6 in baseline and 4.5 during intervention. The mean rating of the level of intensity of side effects experienced by Neil in his experimental context was 4.8 in both baseline and intervention.

#### *Presence or Absence of Difficulty in the Experimental Context*

For each participant, a binary (yes/no) measure was used to document the presence (or absence) of difficulty experienced while participating in the problematic community-based experimental context. Throughout all sessions in baseline, the primary parent raters for all three participants indicated that their respective experimental context was indeed more difficult for their child to successfully complete (i.e., in 100% of the baseline sessions, difficulty was noted in the experimental contexts), as evidenced by data presented in Figure 7, which displays ratings of the level of difficulty for each participant in Study 2. For Jack, difficulty was noted in 40% of the intervention sessions (i.e., 8 out of 20 sessions); however, in 60% of the sessions, his mother indicated that there was no difficulty present while completing the “restaurant” routine. For Ellie, difficulty was noted in 47% of the intervention sessions (i.e., 8 out of 17 sessions); however, her mother indicated that there was no difficulty present while completing the “grocery store” routine in 53% of the sessions. For Neil, difficulty was noted in 71% of the intervention sessions (i.e., 10 out of 14 sessions); however, in 29% of the sessions, his mother indicated that there was no difficulty present while completing the “medical appointment” routine.

### *Level of Difficulty Experienced in the Experimental Context*

As previously described, parents were asked to indicate whether the experimental context was difficult to successfully complete, and for the sessions in which difficulty was noted, they provided ratings of the level of difficulty that was experienced, using a 5-point Likert scale (values ranging from 1 “mild” to 5 “severe”). Figure 7 displays the level of difficulty ratings for each participant in Study 2. For all three participants, the level of difficulty experienced while completing the community-based experimental context was rated in the *severe* range (i.e., level of difficulty was rated a “4” or “5” on the 5-point Likert scale) for 100% of the baseline sessions. For Jack, all of the sessions in baseline were identified as being difficult to complete, and the mean rating of the level of difficulty was 4.4. During intervention, the mean rating of the level of difficulty for the eight sessions that were identified as being difficult to complete was 1.9; the mean rating fell within the *mild* range on the 5-point Likert scale. In baseline for Ellie, difficulty was noted in all sessions, and the mean rating of the level of difficulty was 4.9. During intervention, only eight sessions were identified as being difficult to complete, and the mean rating of the level of difficulty for these sessions was 2.2; thus the mean rating fell within the *moderate* range on the 5-point Likert scale. For Neil, all of the baseline sessions were identified as being difficult to complete, and the mean rating of the level of difficulty was 4.8. During intervention, difficulty was noted in ten sessions, and the mean rating of the level of difficulty was 1.9; thus, the mean rating fell within the *mild* range on the 5-point Likert scale.



### *Overall Level of Problem Behavior Severity*

Parents were asked to rate the level of severity of the problem behavior exhibited by their child in their respective community-based experimental contexts, using a 5-point Likert scale (values ranging from *mild to severe*). Figure 7 displays parent ratings of the level of problem behavior severity for each participant in Study 2. Throughout all of the baseline sessions, parents reported that their child demonstrated *severe* levels of problem behavior while participating in their problematic routines (i.e., the level of severity was rated either a “4” or “5” on the 5-point Likert scale). For Jack, problem behavior was displayed in all sessions of baseline, and the mean rating of the level of problem behavior severity was 4.4. However, during intervention, problem behavior was demonstrated in 7 out of 20 sessions, and the mean rating of the level of severity for these sessions was 1.9, which fell within the *mild* range on the 5-point Likert scale. For Ellie, problem behavior was exhibited in all baseline sessions; the mean rating of the level of problem behavior severity was 4.8. During intervention, however, she displayed problem behavior in 9 out of 17 sessions, and the mean rating of the level of severity for these sessions was 1.9, which fell within the *mild* range on the 5-point Likert scale. Problem behavior was demonstrated by Neil in all baseline sessions, and the mean rating of the level of problem behavior severity was 4.9. During intervention, he exhibited problem behavior in 8 out of 14 sessions, and the mean rating of severity was 2.4, which fell within the *moderate* range on the 5-point Likert scale. In sum, following intervention, the number of sessions in which problem behavior was displayed had been substantially reduced for all participants.

## STUDY 3: TRANSITION-BASED ROUTINES AS A CONTEXT FOR PROBLEM BEHAVIOR

### Method

#### *Overview*

All the procedures outlined in the Overview sections of Studies 1 and 2 were repeated in Study 3 for a different group of three families. This process resulted in the selection of three participants, ranging in age from 9 to 19 years old, for whom families identified a transition-based routine as the priority (experimental) context (i.e., the activity that had become more problematic for their child since going on their current medication, due to the presence of side effects and ultimately resulting in an exacerbation of problem behavior). Specifically, the experimental contexts included: for Alana “transitioning to and from the car,” for Adam “the morning transition to school,” for Mark, and “transitioning between locations during community outings.”

A multiple baseline design across three participants (Hersen & Barlow, 1976) was conducted in Study 3 to examine the potential impact of an intervention package, comprised of mitigation and coping strategies, on problem behavior displayed during problematic transition-based routines.

#### *Participant and Context Selection*

##### *Participant 1: Alana*

Alana was a 9-year-old girl, diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified (Full Scale IQ = 53, Wechsler Intelligence Scale for Children, Fourth Edition), who lived at home with her mother, father, younger sister, and live-in au pair. She was placed in a self-contained special education classroom in a local public

school. Alana had limited verbal abilities, and communicated primarily through the use of single words and gestures, and had recently begun using picture symbols to make simple requests.

*Medication and Side Effects Profile.* Alana's medication regimen at the time of the study included: carbamazepine (400 mg/day administered in the morning and evening), paroxetine hydrochloride (20mg/day administered in the morning) and clonazepam (1mg/day administered in the morning, afternoon, and evening).

Alana's mother reported that since going on the current combination of medication, she noticed the presence of the following side effects: fatigue or lethargy, episodes of haziness/difficulty concentrating, and more frequent changes in mood accompanied by periods of intense crying. Specifically, she stated that Alana became markedly more fatigued (i.e., she appeared physically drowsy, often attempted to lay down/rest, and frequently yawned and closed her eyes) within approximately 20-30 minutes of taking her medication; the sedation tended to last for 1-2 hours before subsiding. Her mother also noted that Alana seemed to experience distinct episodes of increased haziness and difficulty concentrating, when she became noticeably less responsive and less engaged (i.e., she had a fixed gaze and was often motionless for extended periods of time). She stated that these staring spells tended to be more frequent earlier in the day, and rarely occurred in the evenings. Additionally, she noted that her daughter experienced more frequent and intense changes in mood since going on the most current combination of medication. She reported that Alana's mood seemed more unpredictable, as she would suddenly become excessively distressed followed by periods when she would cry uncontrollably, with seemingly little provocation.

*Context Selection.* Alana's mother participated in the initial assessment, and was administered the SIAMSE. According to her responses, she indicated that "transitioning to and from the car" was the most problematic activity for Alana since she had started the most current combination of medication (i.e., this routine was rated a 5 "much more difficulty to complete" on the 5-point Likert scale that measured the level of difficulty experienced during home and community routines); thus, this routine was selected as the experimental context, and became the focus of the intervention. Specifically, her mother stated that when medication side effects were present, namely increased fatigue, episodes of haziness and reduced responsiveness, and increased emotionality and crying spells, they greatly interfered with Alana's ability to complete the transition-based routine, and ultimately resulted in an exacerbation of problem behavior displayed in this context. During follow-up assessment, Alana's mother noted that transitions between locations had typically been an area of difficulty for her daughter; however, this routine became even more aversive and challenging for Alana to complete in a timely manner when she was fatigued and when she experienced episodes of haziness and difficulty concentrating, as she was much slower to respond to directives, her physical movements were noticeably more sluggish, and she became more easily frustrated and agitated when presented with task demands or requests. Consequently, when she experienced greater difficulty completing this transition-based routine, her mother explained that Alana was much more likely to display more severe levels of problem behavior (e.g., noncompliance, dropping to the floor, and tantrums) in this context than had been the case prior to going on the current medication regimen.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional routines that had become more problematic since going on the current combination of medication, seemingly due to the presence of side effects. These activities were identified as the clinical extension contexts, and included: “getting dressed”, “grooming (e.g., showering, brushing teeth),” and “going to restaurants.” Although data collection did not occur in these contexts, Alana’s family was provided with additional mitigation and coping strategies to address difficulties encountered while completing these routines.

*Participant 2: Adam*

Adam was a 13-year-old young man diagnosed with Autistic Disorder and Obsessive Compulsive Disorder (Full Scale IQ = 67, Stanford-Binet Scales of Intelligence, Fifth Edition), who resided at home with his mother, father, and younger twin sisters. He attended a private school that provided services to individuals with developmental disabilities. Adam communicated primarily through the use of complete, short sentences, and often engaged in delayed echolalia (i.e., repeating certain words or phrases), especially when he became anxious or distressed.

*Medication and Side Effects Profile.* Adam’s medication regimen throughout the course of the study included: aripiprazole (30mg/day administered in the morning, noon, and evening), topiramate (100mg/day, administered in the morning and evening), catapres (3mg/day administered in the morning and evening), trazadone hydrochloride (300mg/day, administered in the morning and evening), and lorazepam (6mg/day, administered in the morning, noon, and evening).

Adam's mother reported that since starting this current combination of medication, she had noticed the presence of the following side effects: increased fatigue, headaches, elevated levels of anxiety, as well as a marked increase in irritability and agitation. Specifically, she stated that Adam was noticeably more fatigued (i.e., he appeared physically drowsy, and his motor movements and overall responding to stimuli was delayed) following the administration of his medication. She noted that he became more lethargic within 30-40 minutes of taking his medication, and this tended to last approximately 1-2 hours, after which, he became distinctly more alert and energetic. Additionally, his mother stated that Adam more frequently complained of having headaches, which tended to occur in the late afternoon, and she noticed he would squint and rub the sides of his head more frequently during this time. She also noted that Adam's level of anxiety seemed elevated, and she explained that he more frequently engaged in a ritual of repetitive questioning or commenting about anxiety-provoking events or situation. Further, she stated that in the mornings, she noticed that Adam seemed much more irritable and easily agitated by minor annoyances and certain environmental stimuli (e.g., loud or sudden sounds, bright or flashing lights, crowded or chaotic settings) than he had been prior to going on the current regimen of medication.

*Context Selection.* Adam's mother participated in the initial assessment, and was administered the SIAMSE during the assessment phase of the study. She reported that the "morning transition to school" had become the most problematic routine for Adam since starting the most current medication regimen (i.e., this routine was rated a 5 "much more difficulty to complete" on the 5-point Likert scale that measured the level of difficulty experienced during home and community routines); thus, this routine was

selected as the experimental context, and became the focus of the intervention.

Specifically, his mother stated that when medication side effects were present, namely fatigue, increased anxiety, greater levels of irritability and agitation, they greatly impeded Adam's ability to successfully complete the transition-based routine, and ultimately resulted in an exacerbation of problem behavior that was displayed in this context.

During follow-up assessment, his mother explained that when Adam was fatigued, he tended to experience greater difficulty concentrating or maintaining his focus/attention, his movements were slow and sluggish, and his tolerance for frustration was greatly reduced, as he often became extremely distressed when presented with requests or task demands. Additionally, she noted that when Adam experienced elevated levels of anxiety, it became much more difficult for him to attend to tasks or to follow directions, as he tended to perseverate on the anxiety-provoking topic, engaging in a ritual of repetitive questioning. Further, she explained that it was extremely challenging to redirect his attention back to task once the ritual began, as he became more anxious when attempting to interrupt the repetitive behaviors. Thus, she indicated that when these side effects were present, the routine of transitioning to school became much more aversive and challenging for her son to complete in a timely manner, and consequently, when Adam experienced greater difficulty completing the morning transition routine, he was much more likely to display more severe levels of problem behavior (e.g., aggression, self-injurious behavior, property destruction, tantrums) in this context than had been the case prior to starting the current medication combination.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional activities that had become more

problematic since going on the current combination of medication, seemingly due to the presence of side effects. These routines were identified as the clinical extension contexts, and included: “shopping” and “completing household chores.” Although data collection did not occur in these contexts, Adam’s family was provided with additional mitigation and coping strategies to address difficulties encountered while completing these activities.

*Participant 3: Mark*

Mark was a 19-year-old young man diagnosed with Autistic Disorder and Obsessive Compulsive Disorder (Full Scale IQ = 65, Leiter International Performance Scale, Revised), who resided at home with his mother and father. He attended a private school that provided services to individuals with developmental disabilities. Mark demonstrated significant delays in verbal communication, and he primarily relied on short phrases, gestures and simple picture symbols to communicate with others.

*Medication and Side Effects Profile.* Mark’s medication regimen throughout the course of the study included: oxcarbazepine (1200mg/day, administered in the morning and evening), risperidone (3.5mg/day administered in the morning and the evening), and fluoxetine (50mg/day administered in the evening).

Mark’s mother reported that since starting this current combination of medication, she had noted the presence of the following side effects: increased irritability and agitation, fatigue, increased haziness/confusion (difficulty concentrating), and more frequent gastrointestinal discomfort and diarrhea. Specifically, she noted that Mark was much more irritable and physically agitated, as he seemed to be more restless, and she noticed that he more frequently engaged in repetitive, self-stimulatory behaviors (e.g.,



pacing back and forth; rocking his body repetitively), particularly in the later afternoon and in the evening. She stated that her son was noticeably more fatigued (i.e., he appeared physically drowsy, and his motor movements were delayed) approximately 30 minutes after taking his medication. Moreover, she reported that the sedation tended to last up to 2 hours, after which he seemed to be more alert, engaged, and physically active. Mark's mother also explained that he appeared to experience periods of "haziness" or "cognitive dulling," when he seemed to have greater difficulty concentrating or attending to a particular task. Importantly, she stated that these periods of haziness tended to occur following administration of his medication, and became less evident later in the day. Additionally, she stated that since starting the most current dosages of medications, Mark appeared to experience more frequent and intense gastrointestinal discomfort (e.g., cramping, gas, bloating) and episodes of diarrhea, as she noticed that he often rubbed his stomach, or made gestures indicating that his stomach hurt (typically occurring prior to a bout of diarrhea).

*Context Selection.* Mark's mother participated in the initial assessment, and was administered the SIAMSE. She indicated that since starting the most current medication combination, Mark appeared to experience much greater difficulty participating in activities that involved transitioning between locations (i.e., this routine was rated a 5 "much more difficulty to complete" on the 5-point Likert scale that measured the level of difficulty experienced during home and community routines). Thus, "transitioning between locations during community outings" was selected as the experimental context, and became the focus of the intervention. Specifically, she stated that when medication side effects were present, including increased levels of fatigue, episodes of haziness and

impaired concentration, more intense irritability/agitation, and gastrointestinal discomfort (cramping, diarrhea), they greatly interfered with Mark's ability to appropriately transition between locations while in the community, and in turn, eventually led to an exacerbation of problem behavior that was displayed in this routine.

During the follow-up assessment, his mother indicated that transitioning between settings became much more aversive and difficult for Mark to successfully complete when he was fatigued and experiencing periods of haziness/difficulty concentrating, as his physical movements were noticeably slower and more sluggish, and tended to have a reduced tolerance for frustration, often becoming increasingly distressed when presented with task demands, requests, or when he was asked to wait. In addition, she reported that when he appeared to be experiencing gastrointestinal discomfort and bouts of diarrhea, he became much more irritable, less tolerant of demands, and he seemed more withdrawn, preferring to be alone (i.e., he more readily sought to isolate himself instead of seeking out others for comfort). She explained that when these symptoms were present, most activities and tasks took longer for him to complete and became more difficult for him; however, she noted that transitioning in the community became particularly challenging. Consequently, when he experienced greater difficulty completing this transition-based routine, his mother explained that Mark was much more likely to display more severe levels of problem behavior (e.g., noncompliance, tantrums, self-injurious behavior, and property destruction) in this context than had been the case prior to going on the current medication regimen.

Following the successful implementation of the intervention package in the experimental context, the family nominated additional activities/routines that had become

more problematic since going on the current combination of medication, seemingly due to the presence of side effects. These activities/routines were identified as the clinical extension contexts, and included: “completing household chores,” “shopping,” and “going to restaurants.” Although data collection did not occur in these contexts, Mark’s family was provided with additional mitigation and coping strategies to address difficulties encountered while completing these activities.

### *Baseline Observations*

As outlined in Studies 1 and 2, the baseline phase of this study was divided into two components, an initial validation baseline phase and an extended baseline phase. Following the completion of five validation sessions, each family entered the extended baseline phase. Throughout both baseline components, direct observations were conducted by multiple informants in the experimental context identified by each family to assess: the percentage of task steps successfully completed in that context, the latency to problem behavior, and the reason for session termination. In addition, parents were asked to collect ancillary data to assess: the level of intensity of their child’s medication side effects, the level of difficulty in successfully completing the specified experimental context, and the overall level of problem behavior displayed by their child in that routine. The same observation and data collection procedures were utilized in both the initial validation phase as well as in the extended baseline phase. For each family, one parent was identified as the primary parent rater, and was responsible for the ongoing data collection throughout the baseline and intervention conditions. A second caregiver conducted observations and collected data in the experimental contexts on multiple occasions during both components of baseline, as well as in the intervention condition.

The investigator (the first author) conducted multiple direct observations and collected data in the experimental contexts of all the participants to confirm that the specified activity/routine was associated with the occurrence of problem behavior, and that a low percentage of transition steps were completed. On several occasions throughout both components of baseline and during intervention, a second observer, who was blind to the hypotheses, also conducted direct observations and collected data in the experimental context for all participants.

A task analysis was developed for the experimental contexts, to measure each child's progress in completing the problematic routine. Recall that for Alana, the experimental context identified by her mother was "transitioning to/from the car," and the sequence of steps for this routine included: (1) Alana prepared to leave the house (i.e., she put on her shoes and coat); (2) Alana exited the house and walked to the car (3) Alana entered the car and put on her seatbelt; (4) upon arrival to the destination, Alana exited the car within 1 min of her mother opening the door and asking her to exit. The experimental context identified by Adam's parents was the "morning routine transition to school." The steps involved in this activity included: (1) Adam prepared to leave the house (i.e., he put on his coat and took his backpack) within two minutes of an adult delivering the verbal discriminative stimulus "It is time to go to school." (2) Adam exited the house and walked to the bus; (3) Adam got on the bus, sat down, and buckled his seatbelt; (4) upon arriving at school, Adam exited the bus and walked into the school building (accompanied by a teacher). For Mark, "transitioning between locations during community outings (e.g., from the library or video store)" was identified as the experimental context. The sequence of steps for this routine included: (1) Mark exited the

library or video store within 2 min of his parent delivering the verbal discriminative stimulus “It is time to go home,” (2) Mark walked to the car, got in and put his seatbelt on; (3) upon arriving at home, Mark exited the car within 1 min of a parent opening the door and asking him to exit; (4) Mark walked to and entered the house.

To ensure the safety of the child and the parent, a session was terminated contingent upon the demonstration of problem behavior defined as either : (1) the occurrence of a single instance of “untolerated” problem behavior, namely, aggression (e.g., hitting, dropping to the floor, kicking) or self-injurious behavior (e.g., biting hand, hitting head), or more than 5 seconds of screaming (Carr & Carlson, 1993), or (2) three instances of “tolerated” problem behavior, defined as brief episodes (i.e., less than 5 seconds) of screaming, verbal protests, and/or stomping feet on the floor. Tolerated problem behavior was seen as less serious by the parents and, thus, up to three instances of such behavior were allowed prior to the termination of the session.

#### *Response Recording*

Data collection procedures for this study were similar to those described in Studies 1 and 2. Multiple informants collected data to measure several primary dependent variables including: (a) percentage of task steps completed, (b) latency to session termination due to the occurrence of problem behavior or successful completion of the community-based activity, and (c) the reason for session termination. As in Studies 1 and 2, the primary parent rater and a second caregiver (on multiple occasions) collected additional data to measure several ancillary dependent variables that included: (a) recordings (i.e., binary yes/no measure) that indicated the presence or absence of medication side effects in the experimental context, (b) ratings of the level of intensity of

the side effects that were present (using a 5-point Likert scale), (c) recordings (i.e., binary yes/no measure) indicating the presence or absence of difficulty experienced while completing the community-based activity, (d) ratings of the level of difficulty that was experienced during completion of the experimental context (using a 5-point Likert scale), and (e) ratings of the overall level of severity of problem behavior displayed by the child in the routine (using a 5-point Likert scale).

### *Development of the Intervention*

Following a period of baseline, an intervention package was developed and subsequently implemented in each experimental context. Evidence-based practices were used to mitigate the negative impact of the side effects and to teach the child coping skills so that he/she could more effectively deal with the side effects, and ultimately be able to more successfully complete the problematic context, thereby resulting in a decrease in the level of problem behavior. Once the intervention package was implemented in the experimental context, the investigator taught the families several additional strategies which they implemented in the clinical extension contexts. The decision processes for initiating, continuing, and terminating the intervention in the experimental context are outlined in Appendix E. The rationale for implementing each component of the intervention package for participants in all three studies is shown in Appendix D.

Each family directly participated in the development of the unique intervention package, utilizing a problem solving approach, as outlined in Appendix C. Although each package followed a generic model using mitigation and coping strategies, the precise nature of each strategy was determined by the specific properties for each context, including the characteristics of the various side effects that were parent. Interventions

were implemented that the families considered user-friendly and feasible, following procedures using a goodness of fit assessment described in Appendix H (Albin et al., 1996).

*Participant 1: Alana*

Transitions between settings and/or activities have been found to trigger problem behavior (Schmidt et al, 2000). Studies have suggested that the lack of predictability associated with transitions may in fact play a significant role in evoking problem behavior for individuals with developmental disabilities (Flannery & Horner, 1994). Recall that “transitioning to and from the car” was identified as the experimental context for Alana. Specifically, her mother noted that when side effects were present they appeared to make transitioning much more difficult for her, and, in turn, Alana displayed more severe levels of problem behavior when attempting to complete this routine. To address the difficulties experienced, an intervention package was created that was comprised of several mitigation and coping strategies.

*Mitigation Strategies for transitioning to and from the car.* The use of a *visual schedule* depicting upcoming events or the specific sequence of steps involved in a particular activity has been found to be an effective strategy for addressing problematic activities because schedules tend to reduce the unpredictability associated with the task, as the child is better informed about the steps involved in completing the task (MacDuff, Krantz, & McClannahan, 1993; Quill, 1995). Further, children diagnosed with autism are often described as “visual learners;” thus, the use of visual supports would seemingly capitalize on this area of relative strength in visual processing skills (McClannahan & Krantz, 1999). Research has demonstrated that visual schedules are effective in reducing

problem behavior exhibited during transitions (Mesibov, et al., 2002). Therefore, to enhance the predictability of Alana's transition routine, we created a visual schedule depicting the sequence of steps involved in the routine. According to her mother, Alana enjoyed looking at photographs, which was confirmed upon conducting a preference assessment; thus, we created a portable visual schedule for her that was comprised of photographs of the various steps involved in the transition to and from the car. Her mother presented the schedule to Alana throughout the course of the transition, and as each step was completed, she removed the corresponding picture and placed it in an envelope that was pasted on the back of the clipboard.

As noted previously, providing a *visual representation of time* has been found to be a useful strategy for increasing predictability and reducing problem behavior when children with developmental disabilities are required to transition between settings and/or activities (Dettmer et al., 2000). Therefore, a visual timer was included in the intervention package created for Alana. Five minutes prior to the transition, Alana's mother set a timer and showed it to her. She also delivered a verbal warning alerting her to the amount of time remaining until the transition would be begin (e.g., "1 more minute until it is time to put on your shoes and jacket and get into the car"). This procedure helped enhance predictability and gave Alana advanced notice that she would need to prepare for the upcoming transition to the car.

Another mitigation strategy that has been found to effectively reduce problem behavior associated with transitioning between settings is the *use of a transitional item* (Cameron et al., 1992). Additionally, introducing a stimulus associated with appropriate behavior into a context typically associated with problem behavior is often found to



correlate with a reduction in problem behavior (Gardner et al., 1986). Therefore, to help Alana more successfully transition to and from the car in the absence of problem behavior, a transitional item was provided prior to the beginning of the transition. We used items that were highly preferred and that promoted a high level of arousal and engagement (e.g., hand held instruments such as drum sticks, a tambourine, a small radio playing a favorite song, etc.).

*Coping Strategies for transitioning to and from the car.* Research has shown that *providing opportunities for making choices* in activities that are disliked or difficult can result in decreases in problem behavior (Bambara et al., 1995; Shogren et al., 2004) as well as increased task engagement (Dunlap et al., 1994). Therefore, to reduce the likelihood that she would display problem behavior and to enhance motivation to appropriately transition to and from the car, we included frequent opportunities for Alana to make choices throughout the routine (e.g., choice of transitional item she carried to and from the car, choice of where she sat in the car, choice of music they listened to in the car).

According to her mother, Alana tended to experience less difficulty with transitions when her arousal level was increased and she engaged in more vigorous movements just prior to the start of the transition routine. Therefore, we taught Alana to regulate her arousal level by engaging in brief alerting activities (e.g., bouncing on a therapy ball, jumping or running in place for several seconds, doing several stretching exercises, jumping on a mini-trampoline) before transitioning to the car. Additionally, during the car ride Alana was given a small purse that contained several small objects (e.g., therapeutic balls, strings, beads) that she could manipulate (i.e., pull, shake,

squeeze, tangle and untangle) to maintain her arousal level and keep her engaged, especially prior to the transition from the car. Her mother prompted her to play with one of the manipulatives in her bag and gave her a verbal warning alerting her when they were one minute away from home. Thus, Alana learned to *self-regulate and engage in arousing exercises and activities* to help cope with the side effects that negatively impacted a variety of home and community contexts.

*Clinical Extension.* Alana's mother identified additional activities that had become more difficult for her to successfully complete since going on the current combination of medication due to the presence of adverse side effects. Although there was no experimental demonstration included in this portion of the study, additional mitigation and coping strategies were developed and implemented to address problem behavior in the following clinical extension contexts: (a) "getting dressed," (b) "grooming," (c) "going to the grocery store," and (d) "the bedtime routine." As noted previously, the use of visual supports has been found to reduce problem behavior displayed by individuals with autism (Mesibov et al., 2002). Therefore, to enhance predictability in these difficult routines, visual schedules were created for the getting dressed, grooming, and grocery store routines. The schedules were constructed on portable clipboards, and were comprised of a series of photographs depicting the sequence of steps involved in the various routines.

Studies have shown that allowing a child to make choices (express preferences) in aversive activities can reduce problem behavior and increase compliance (Clarke et al., 1995). Therefore, to increase her compliance during the activities and enhance her motivation to appropriately complete these tasks, Alana was provided with opportunities

to make choices throughout these activities. For example, when she was getting dressed, she was given the opportunity to choose among different items of clothing to wear (e.g., her mother presented her with two different shirts and asked her to choose the one she wanted to wear). In addition, we embedded a preferred activity, into the grooming routine to increase compliance and reduce the likelihood of problem behavior. Specifically, Alana was presented with a choice of CDs she could listen to while completing this disliked/difficult task, and the music was put on as long as she displayed appropriate behavior during the routine.

*Participant 2: Adam*

Individuals with autism commonly experience difficulties with transitions (Kern, & Vorndran, 2000). Researchers have suggested that problems associated with transitions are often related to the lack of predictability, and studies have demonstrated that interventions aimed at enhancing predictability are effective in reducing problem behavior displayed by individuals with developmental disabilities (Flannery & Horner, 1994; Tustin, 1995). Recall that for Adam “the morning transition to school” was identified as the experimental context. Specifically, his parents stated that when the various medication side effects were present, they appeared to negatively impact the transition routine (e.g., this routine became more aversive and difficult to complete), and consequently, problem behavior was commonly displayed in this context. Thus, to address these difficulties experienced in the experimental context, an intervention package was created, composed of several mitigation and coping strategies.

*Mitigation Strategies for Morning Transition to School.* Individuals with autism spectrum disorder have been described as being visual learners, and studies have found

the use of visual supports reduces problem behavior (McClannahan & Krantz, 1999). Further, research has demonstrated that visual schedules are useful for addressing difficulties with transitioning between settings, as they reduce the unpredictability often associated with transitions (Mesibov et al., 2002). Therefore, to enhance the predictability of the transition to school, we created a *visual schedule* depicting the sequence of steps involved in the routine. Adam was presented with a portable clipboard that had pictures and printed words representing the various steps comprising the transition. Following the last picture on the schedule, Adam was allowed to choose another picture to represent a preferred activity that he could engage in upon completing the transition to school.

Studies have also shown that providing a *visual representation of time* can be an effective strategy for increasing predictability and decreasing problem behavior associated with transitions (Dettmer et al., 2000). Therefore, a timer was included as a mitigation strategy to address difficulties experienced during the morning transition to school. Each morning the bus staff assigned to work with Adam called the house to alert them when they were 5 minutes away, and his parents subsequently set an egg timer and showed the time to him. This procedure provided Adam with an opportunity to see the amount of time he had left before the routine began, and helped him prepare himself for the impending transition. Furthermore, studies have shown that providing advanced warnings of upcoming events can reduce problem behavior in children with autism (Mace, Shapiro, & Mace, 1998; Tustin 1995). Thus, in addition to the timer, his parents delivered *advanced verbal warnings* periodically during the 5 minute interval to alert Adam of the time remaining until the bus arrived.

*Coping Strategies for Morning Transition to School.* Research has suggested that *providing access to a preferred object during a nonpreferred activity* can result in reductions of problem behavior displayed by individuals with developmental disabilities (Cameron et al., 1992). The preferred object essentially functions as a discriminative stimulus for appropriate behavior (i.e., non problem behavior) that competes with stimuli present in the problematic context triggering and maintaining the problem behavior. Furthermore, studies have shown that providing an individual with a transitional item during difficult transitions is an effective strategy to reduce problem behavior (Gardner et al., 1986). Therefore, Adam was taught to *request a transitional item* to take with him as he transitioned to school to help him more appropriately cope with difficulties experienced during this routine. Specifically, he was prompted to request a portable CD player, and he was given an opportunity to choose a favorite CD to listen to throughout the transition to the bus and into school. This transitional item was a highly preferred object that was associated with appropriate (nonproblem) behavior. Further, listening to music was found to have a positive effect on his mood and overall level of agitation, as it appeared to induce a state of relaxation and seemed to provide a sufficient distraction from some of the aversive aspects of this routine when side effects were present.

*Choice making* has been documented as an effective strategy for reducing problem behavior, as this process provides the child with the opportunity to select preferred stimuli and avoid nonpreferred stimuli, and enhances motivation (Bambara et al., 1995; Cole & Levinson, 2002; Dunlap et al., 1991). Therefore, to increase his compliance during the transition-based routine and reduce the likelihood of problem behavior, Adam was provided with several choice making opportunities throughout the

transition. Specifically, he was given the choice of the shoes he wore to school, the CD he brought to listen to during the transition, and where he sat on the bus. In addition, prior to leaving the house, he was also presented with two pictures representing preferred activities that he could engage in upon arriving at school (without engaging in problem behavior during the transition), and he was asked to choose an activity. This visual representation of the chosen activity was subsequently placed at the bottom of his visual schedule to cue him about the reinforcer that would be available following successful transition to school.

According to his mother, Adam appeared to experience a marked increase in anxiety level since going on the current regimen of medication. As stated previously, she noticed that he seemed more anxious and physically tense, and she reported that he more frequently engaged in a ritual of repetitively asking questions or repeating certain phrases as his level of anxiety increased. Further, she stated that this anxiety-related behavior had a negative impact on the morning transition routine, as once this ritual started it greatly interfered with Adam's ability to complete the various steps of the activity. Thus, to address some of the anxiety-related difficulties he experienced during the morning transition, we taught Adam several *relaxation techniques* including a deep breathing exercise and a simple progressive muscle relaxation exercise (Cautela & Groden, 1978). Research has shown that teaching individuals with developmental disabilities to use relaxation strategies can be effective in reducing anxiety and problem behavior (Mullins & Christian, 2001). Adam's parents practiced these techniques with him approximately five days per week during times when he was calm and typically when he was engaged in a preferred activity to ensure that it was associated with positive experiences and not

perceived as a task demand. Upon noticing early signs of increasing anxiety, Adam's parents modeled the techniques and then prompted him to use them.

*Clinical Extension.* Adam's mother identified additional activities that had become more difficult for him to successfully complete since going on the current medication regimen, due to the presence of adverse side effects. Although there was no experimental demonstration included in this portion of the study, additional mitigation and coping strategies were developed and implemented to address problem behavior in the following clinical extension contexts: (a) "household chores," and (b) "shopping." As noted previously, visual representations of the sequence of steps involved in difficult or disliked activities have been associated with increased predictability and decreased problem behavior in individuals with developmental disabilities (Mesibov et al., 2002). Therefore, a visual schedule was created for both the household chores routine and the shopping activity. The schedules were constructed on portable clipboards that had pictures and printed words representing the various steps comprising the activities. At the bottom of each schedule was a spot for Adam to place a picture representing a chosen preferred activity that he could engage in upon completion of the routine.

Studies have shown that shorter tasks may result in increased productivity and reduced levels of problem behavior in individuals with developmental disabilities (Sweeney & LeBlanc, 1995). Therefore, to reduce some of the aversive aspects of the household chores routine, particularly when side effects were present, we modified the routine by breaking it up into shorter tasks. In addition, the household chores were interspersed among easier and preferred activities that were not associated with problem behavior. For example, Adam was expected to do one chore (e.g., unload the cups from

the dishwasher) and then help his father take their dog for a walk (a preferred activity). Upon returning from the walk, he was expected to complete another chore (e.g., vacuum the floor), and then he was able to engage in a preferred activity (e.g., watching a video for ten minutes). Research has also shown that replacing problem behavior with functionally equivalent communication skills can reduce problem behavior (Carr & Durand, 1985). Studies have demonstrated that teaching requests for help with difficult tasks is associated with decreased levels of problem behavior (Reichle et al., 2002). Therefore, we taught Adam to ask his parents for help with chores when he was experiencing difficulty. Specifically, he was prompted to verbally say “help me, please” upon first signs of distress or if he appeared to experience difficulty. This procedure was used to prevent an escalation of frustration by providing him with a more appropriate means of eliciting assistance.

In addition to implementing a visual schedule in the shopping routine, we created another visual support to enhance predictability, namely, a calendar for the family to use that displayed various community outings, and so Adam and his family would be informed of when upcoming shopping trips were going to occur. This made the shopping routine more predictable for Adam, as his mother reviewed the calendar with him several days prior to the trip. During the problematic shopping routine, Adam was taught to request a transitional item (i.e., his CD player) to bring with him and use while he appropriately completed this routine.

### *Participant 3: Mark*

As noted previously, transitions between locations and activities have consistently been found to be difficult for individuals with autism, and are often associated with



problem behavior (Schmidt et al., 2000). The lack of predictability associated with transitions has been found to play a role in contributing to the occurrence of problem behavior (Flannery & Horner, 1994). Studies have shown that interventions which increase predictability are effective in reducing problem behavior displayed by individuals with developmental disabilities (Flannery & Horner, 1994; Tustin, 1995). Recall that “transitioning during community outings” was identified as the experimental context for Mark. Specifically, his mother noted that this transition-based activity became much more difficult for her son to complete appropriately when side effects were present, ultimately evoking greater levels of problem behavior in this context. To address the difficulties experienced, an individualized intervention package was created that was comprised of several mitigation and coping strategies.

*Mitigation Strategies for Transitions during Community Outings.* Mark’s mother noted that since going on the most current medication regimen and experiencing greater levels of fatigue and irritability, transitions between community locations (e.g., video stores, library, 7-11, comic book store) had become more problematic. The use of visual schedules has been found to decrease problem behavior and increase on-task/attending behaviors, as they enhance predictability by providing the individual with information about the sequence of upcoming events /tasks (McClannahan et al, 1997; Mesibov et al., 2002). To mitigate some of the aversive qualities of the activities he was expected to engage in, when experiencing side effects, we created a *portable visual schedule* for Mark to use during shopping trips in the community (involving multiple transitions). The schedule was comprised of picture icons displaying the locations of each place they would go during that day’s outing; this helped enhance his awareness of upcoming

events. In addition, Mark was provided with the *opportunity to choose a preferred activity* that he could engage in upon returning home from the outing. A picture of the activity was posted at the bottom of the schedule to serve as a visual reminder of an preferred event that he could “look forward to,” thus, serving as incentive for participating appropriately while shopping in the community.

Another mitigation strategy included in the intervention package developed to address difficulties experienced by Mark in the transition-based routine was the use of *video self-modeling*. Research has demonstrated the efficacy of video technology to teach individuals with autism a wide variety of appropriate skills such as spontaneous requesting, play-related behaviors, perspective taking, and daily living skills (Charlop-Christy & Daneshvar, 2003; Shipley-Benamou, Lutzker, & Taubman, 2002), and studies have shown that video modeling can be an effective strategy for reducing disruptive behaviors associated with transitions (Schreibman, Whalen, & Stahmer, 2000). Video modeling is a behavioral technique that utilizes videotape rather than live scenarios to demonstrate and teach desired behaviors or skills. Video self-modeling is a variant of this strategy in which the individual is filmed performing a target skill or behavior, and the tape is subsequently edited in a manner to ensure it contains primarily successful demonstrations of the target behavior for the child to view (Bellini & Akullian, 2007; Dorwick, 1999). The use of video technology with this population appears to be an effective intervention strategy, as children with autism spectrum disorders are often described as visual learners; thus, utilizing video to teach and model appropriate behavior capitalizes on this relative strength in visual processing skills (McClannahan & Krantz, 1994). Further, the use of video can be highly motivating, as watching television is often

found to be reinforcing for many children, hence, instruction essentially becomes embedded within a preferred activity when using video modeling strategies. According to his mother, watching videos was a highly preferred activity for Mark; therefore, video self-modeling was included in the intervention package developed to address difficulties experienced while transitioning during community outings. Specifically, we created a videotape of Mark performing the various steps involved in the transition-based routine (e.g., paying for a movie, walking to the car, exiting the car, walking into the house). The video was edited so that the final version presented to Mark included only positive examples of him completing the transition. The final scene of the video depicted his parents' positive response to his successful completion of the transition, and then showed him engaging in a highly preferred activity that he earned as a reward upon appropriately participating in the routine. Mark and his parents viewed the video on days when community outings were scheduled, and used it as an opportunity to remind him of what he was expected to do during the upcoming transition (i.e., this strategy enhanced predictability). In addition, the video was presented when Mark was calm to ensure that it was associated with positive experiences and that it was not perceived as an instructional task.

The final mitigation strategy that was implemented involved a *neutralizing routine*. This strategy has been found to effectively reduce problem behavior in individuals with developmental disabilities (Horner et al., 1997). Therefore, on days in which Mark was going shopping later in the day, a neutralizing routine, namely, taking a brief rest, was included as a mitigation strategy. Specifically, Mark was allowed to choose where he wanted to rest (in his bedroom or on the couch), and his parents were

instructed not to place any task demands on him during this time. They set a timer representing the time remaining before he needed to get up and start the transition; this procedure made the upcoming transition more predictable for Mark.

*Coping Strategies for Transitions during Community Outings.* Research has suggested that the use of relaxation techniques is often associated with reduced levels of anxiety, agitation, and problem behavior in individuals with developmental disabilities (Mullins & Christian, 2001). Thus, to help alleviate some of the distress that Mark experienced when side effects were present during transition-based routines, we taught him several brief *relaxation techniques*. Specifically, Mark was taught a simple deep breathing exercise and a brief progressive muscle relaxation technique (i.e., tensing and relaxing muscles in his hands, arms, and shoulders) that he was prompted to use during the transition between community locations. In addition, Mark was taught to engage in a distracting activity, namely counting softly to himself, to help relieve some of the distress he experienced during the transition. His parents prompted him to count softly to himself as they transitioned between locations, as a means of distracting himself from the distressing aspects of ending a preferred activity or leaving a preferred place.

Another coping strategy that was included in the intervention package involved providing *opportunities for choice making* throughout the routine. Studies have demonstrated that problem behavior displayed by individuals with developmental disabilities can be reduced by providing opportunities for choice making into problematic activities (Bambara et al., 1994; Dunlap et al., 1994). Prior to going on the community outing, Mark was presented with a visual choice board comprised of several pictures representing preferred activities that he could engage in upon returning from the outing;

he was prompted to choose one activity that would be available contingent upon appropriately completing the routine.

*Clinical Extension.* Mark's mother identified additional activities that had become more difficult for him to successfully complete since going on the current medication regimen, due to the presence of adverse side effects. Although there was no experimental demonstration included in this portion of the study, additional mitigation and coping strategies were developed and implemented to address problem behavior in the following clinical extension contexts: (a) "household chores," (b) "shopping," and (c) "going to restaurants." As noted previously, visual representations of the sequence of steps involved in difficult or disliked activities have been associated with increased predictability and decreased problem behavior in individuals with developmental disabilities (Mesibov et al., 2002). Given the positive response to the use of a visual schedule in the transition routine, we created schedules depicting the sequence of task steps for the clinical extension contexts. Additionally, we incorporated multiple opportunities for choice making throughout the household chores, shopping, and restaurant routines. Specifically, Mark was provided with the opportunity to choose the activity he wished to engage in upon successfully completing these problematic activities. Prior to the start of each of the clinical extension contexts, Mark's mother presented him with two pictures representing the preferred activities, and placed the picture of the activity of his choice at the bottom of his visual schedule to remind him of the upcoming reward.

Neutralizing routines were also included as part of the intervention package to address difficulties experienced when side effects were present during the household

chores and shopping routines. As noted previously, his strategy has been found to be effective in reducing problem behavior displayed during demanding or difficult tasks (Horner et al., 1997). Specifically, when his parents noticed that Mark appeared to be experiencing elevated levels of fatigue following the administration of his medication (i.e., side effects were present), they provided him with an opportunity to take a nap before beginning the household chores routine, and prior to going out shopping or to a restaurant. This strategy aimed to reduce some of the additional difficulty that was caused by the presence of side effects during these disliked and difficult routines, and ultimately, reducing the likelihood that problem behavior would occur in these contexts. The final strategy implemented in the clinical extension contexts involved modifying the duration of the difficult routines, particularly when side effects were present, as they made the activities even more difficult and aversive for Mark. Research has demonstrated that providing shorter tasks may result in reductions of problem behavior and increased on-task behavior and productivity (Sweeney & LeBlanc, 1995). Thus, his mother shortened the duration of the household chores routine (i.e., he was expected to complete only 2 tasks each day instead of completing four chores successively when side effects were present), and reduced the amount of time of the shopping activity.

#### *Training of the Intervention Agent*

Once the intervention package was developed, the investigator trained the intervention agent (for Alana, her mother; for Adam, his mother; for Mark, his mother) to carry out the intervention package. The investigator provided verbal explanation of the procedures and then modeled the use of each of the strategies with the child for a minimum of two sessions. A written description of the intervention components was

given to each intervention agent to use, as needed, as an additional form of support. The intervention agent implemented the multi-component intervention package with verbal feedback from the investigator for one session. Verbal feedback was faded, as the intervention agent implemented the intervention package independently for a minimum of two sessions.

### *Intervention Fidelity*

As delineated in Studies 1 and 2, an intervention fidelity checklist, based on the specific intervention strategies for each participant, was developed to evaluate intervention integrity for the experimental context (see Appendix I, Intervention Integrity Checklist, displaying the intervention components for each participant across all three studies). For each participant, a checklist was created that was uniquely tailored to the strategies for the identified problematic routine. In 60% of both the baseline and intervention sessions for Alana, in 50% of the baseline sessions and 65% of the intervention sessions for Adam, and in 55% of the baseline sessions and 79% of the intervention sessions for Mark, the primary parent raters for each participant and the investigator recorded whether each intervention component was implemented. That is, the primary parent rater and the investigator completed the treatment fidelity checklist by recording a checkmark whenever a specific component of the multicomponent intervention package was implemented by the parent in the experimental context.

### *Interrater Reliability*

Employing the same procedures as in Studies 1 and 2, multiple informants collected reliability data on the independent and dependent variables in the experimental contexts. A binary reliability index was used to assess agreement between the primary

parent rater and the investigator on intervention fidelity, and on the primary dependent variables including: the percentage of context steps completed, latency to session termination, and the reason for session termination. For each session, reliability was scored as either perfect agreement or no agreement. Agreement was defined as both observers recording the implementation of the intervention components, the same number of task steps that were completed in the context that they observed, latency measures that were within 5 seconds of one another, and agreement on the reason for session termination (i.e., due to the occurrence of problem behavior or the successful completion of the activity).

The primary parent rater and the second caregiver rater collected reliability data, in the experimental context, on the primary dependent variables, as well as on ancillary dependent variables including: the presence of medication side effects, ratings of the level of intensity of the side effects, the presence of difficulty experienced in the problematic activity, ratings of the level of difficulty experienced, and ratings of the overall level of problem behavior severity displayed by the child in the experimental context. A binary reliability index was used to assess agreement on all of the dependent variables; thus, for each session, reliability was scored as either perfect agreement or no agreement. The same parameters, as described in Study 1, were used to define agreement for the primary dependent variables.

A second researcher, blind to the hypotheses of the study, was present to observe and collect data in the experimental context on multiple occasions. A binary reliability index was used to assess the agreement between data recorded by the investigator and the second researcher on the percentage of task steps completed, latency to session



termination, and the reason for session termination (due to problematic behavior or successful completion). For each session, reliability was scored as either perfect agreement or no agreement, and agreement was defined using the same parameters that were described previously for these primary dependent variables.

*Participant 1: Alana*

For the experimental context, the primary parent rater and a second caregiver independently (but concurrently) completed reliability checks for 60% of both the baseline and intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of the baseline and intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 60% of the baseline sessions and 65% of the intervention sessions. Agreement on the percentage of task steps completed and the reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 100% of the baseline sessions and 92% of intervention sessions. Agreement on the ancillary dependent variables including the presence/absence of side effects, ratings of the level of intensity of side effects, the presence/absence of difficulty in the experimental context, and ratings of the level of problem behavior severity was noted in 100% of the baseline and intervention sessions. Agreement on the ratings of the level of difficulty experienced in the experimental context was noted in 100% of the baseline sessions and 92% of the intervention sessions.

Reliability checks were also independently (but concurrently) completed by the investigator and the second (blind) researcher for 40% of the baseline sessions, and 45% of the intervention sessions. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

*Participant 2: Adam*

For the experimental context, two observers (the primary parent rater and a second caregiver) independently (but concurrently) completed reliability checks for 50% of the baseline sessions and 65% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 100% of the baseline sessions and 91% of intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 75% of the baseline sessions, and 71% of the intervention sessions. Agreement on the percentage of task steps completed, and reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 83% of the baseline sessions and 92% of the intervention sessions. Agreement on the ancillary dependent variables including the presence/absence of side effects, and the presence/absence of difficulty in the experimental context, was noted in 100% of the baseline and intervention sessions. For 100% of the baseline sessions and 83% of intervention sessions, agreement on the ratings of the level of intensity of side effects

present in the experimental context was noted. Agreement on the ratings of the level of difficulty experienced in the experimental context was noted in 100% of the baseline sessions and 92% of the intervention sessions, and agreement on the ratings of the level of problem behavior severity was noted in 100% of baseline sessions and 83% of the intervention sessions.

For 38% of the baseline sessions and 47% of the intervention sessions, reliability checks were independently (but concurrently) completed by the investigator and the second (blind) researcher. Agreement on the percentage of context steps completed and the reason for session termination was noted in 100% of both the baseline and intervention sessions. Agreement on latency to session termination was noted in 100% of baseline sessions and 88% of the intervention sessions.

*Participant 3: Mark*

For the experimental context, the primary parent rater and the investigator independently (but concurrently) completed reliability checks for 55% of the baseline sessions and 79% of the intervention sessions. Agreement on intervention fidelity, the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and intervention sessions.

In addition, reliability checks were independently (but concurrently) completed by the primary parent rater and the second caregiver rater for 64% of the baseline sessions and 57% of the intervention sessions. Agreement on the percentage of task steps completed, latency to session termination, and reason for session termination was noted in 100% of the baseline and intervention sessions. Furthermore, agreement on the ancillary dependent variables including the presence/absence of side effects, the

presence/absence of difficulty experienced in the experimental context, and the ratings of the level of problem behavior severity was noted in 100% of the baseline and intervention sessions. Agreement on the ratings of the level of intensity of side effects that were present in the experimental context was noted in 86% of the baseline sessions and 75% of the intervention sessions. Agreement on the ratings of the level of difficulty that was experienced in the experimental context was noted in 100% of the baseline sessions and 88% of the intervention sessions.

Reliability checks were also independently (but concurrently) completed by the investigator and the second (blind) researcher for 55% of the baseline sessions, and 43% of the intervention sessions. Agreement on the percentage of context steps completed, latency to session termination, and reason for session termination was noted in 100% of both the baseline and the intervention sessions.

## Results

### *Intervention Fidelity*

In baseline, a mean of 0% of the intervention components were implemented by each parent in their respective contexts. During intervention, a mean of 100% of the intervention components were implemented by each parent in the experimental contexts.

### *Percentage of Steps Completed*

The percentage of transition-based routine steps completed for each participant is displayed in Figure 8. In extended baseline, Alana completed a mean of 10% of the steps that comprised the “transitioning to and from the car” routine. During intervention, however, she completed a mean of 100% of the steps in 15 out of 20 sessions, and a mean of 65% of the steps in the remaining five sessions. Adam, in extended baseline,

completed a mean of 9.4% of the steps that constituted the “morning transition to school” routine. During intervention, he completed a mean of 100% of the steps in 10 out of 17 sessions, and a mean of 64% of the steps in the remaining seven sessions. In baseline, Mark completed a mean of 15.9% of the steps that comprised the “transitioning during community outings” routine. During intervention, however, he completed a 100% of the steps in 11 out of 14 sessions and 75% of the steps in the remaining three sessions.

#### *Latency to Problem Behavior*

Figure 9 displays data on the amount of time that elapsed before the session was terminated (due to either the occurrence of problem behavior or the successful completion of the activity) for the three participants. For Alana, the mean latency to problem behavior displayed during the transition-based routine in baseline was 3 min, 27 s. The mean latency to problem behavior during intervention was 6 min, 10 s in the five sessions that were; however, the mean latency to successful completion of the transition routine (12 out of 20 sessions) was 8 min, 3 s. For Adam, the mean latency to problem behavior displayed during the morning transition to school routine in baseline was 2 min, 35 s. During intervention, mean latency to problem behavior was 5 min, 59 s in the seven sessions that were terminated, and mean latency to successful completion of the transition to school routine (10 out of 17 sessions) was 7 min, 3 s. In baseline, for Mark, the mean latency to problem behavior demonstrated during the transitioning routine was 3 min, 30 s. The mean latency to problem behavior during intervention was 6 min, 28 s in the three sessions that were terminated due to problem behavior, and mean latency to successful completion of the transition routine (11 out of 14 sessions) was 6 min, 20 s.

### *Reason for Session Termination*

Figure 9 shows that sessions could be terminated due to the presence of untolerated problem behavior (indicated by solid black bars), tolerated problem behavior (indicated by solid pink bars), or successful completion of the problematic transition-based activity/routine in the absence of problem behavior (indicated by open bars). For each participant in baseline, all sessions were terminated due to the presence of untolerated and tolerated problem behavior (i.e., none of the baseline sessions were successfully completed). During intervention for Alana, 2 out of 20 sessions was terminated due to untolerated problem behavior (as indicated by solid black bars), and 3 out of 20 sessions were terminated due to tolerated problem behavior (as indicated by grey bars); however, the remaining 15 sessions were successfully completed. For Adam, in intervention, 3 out of 17 sessions were terminated due to untolerated problem behavior, and 4 out of 17 sessions were terminated due to tolerated problem behavior; however, the remaining ten sessions were successfully completed. For Mark, only 3 of the 14 sessions were terminated due to tolerated problem behavior; thus, the remaining 11 sessions were successfully completed.

### *Presence or Absence of Medication Side Effects*

For each participant, a binary (yes/no) measure was used to document the presence (or absence) of the medication side effects experienced in their transition-based experimental context. The primary parent raters for all three participants indicated that medication side effects were in fact present (at elevated levels) in 100% of the sessions throughout baseline and intervention, as evidenced by data presented in Figure 10 which displays ratings of the level of side effect intensity for each participant.

### *Level of Intensity of Medication Side Effects*

As previously noted, parents were asked to rate the level of intensity of the medication side effects that were present in the experimental context, using a 5-point Likert scale (values ranging from “mild” to “severe”). Figure 10 displays ratings (provided by primary parent raters) of the level of intensity of the various side effects that were experienced by each participant in their problematic transition-based activity. For all three participants, the side effect intensity ratings were in the *severe* range (i.e., the level of intensity was rated a 4 or 5 on the 5-point Likert scale) for all sessions throughout the baseline and intervention phases. The mean rating of the level of intensity of side effects experienced by Alana was 4.6 in baseline and 4.5 during intervention. For Adam, the mean rating of the level of intensity of side effects in baseline was 4.5 and 4.6 during intervention. For Mark, the mean rating of the level of intensity of side effects that were present in his experimental context was 4.6 in baseline and 4.3 during intervention.

### *Presence or Absence of Difficulty in the Experimental Context*

For each participant, a binary (yes/no) measure was used to document the presence (or absence) of difficulty experienced while participating in the problematic transition-based experimental context. Throughout all sessions in baseline, the primary parent raters for all three participants indicated that their respective experimental context was indeed more difficult for their child to successfully complete (i.e., in 100% of the baseline sessions, difficulty was noted in the experimental contexts by all parents), as evidenced by data presented in Figure 10 which displays ratings of the level of difficulty for each participant. For Alana, difficulty was noted in 40% of the intervention sessions (i.e., 8 out of 20 sessions); however, in 60% of the sessions, her mother indicated that

there was no difficulty present while completing the “transitioning to/from the car” routine. For Adam, difficulty was noted in 65% of the intervention sessions (i.e., 11 out of 17 sessions); however, his mother indicated that there was no difficulty present while completing the “morning transition to school” routine in 35% of the sessions. For Mark, difficulty was noted in 57% of the intervention sessions (i.e., 8 out of 14 sessions); however, in 43% of the sessions, his mother indicated that there was no difficulty present while completing the “transitions during community outings” routine.

#### *Level of Difficulty Experienced in the Experimental Context*

As previously described, parents were asked to indicate whether the experimental context was difficult to successfully complete, and for the sessions in which difficulty was noted, they provided ratings of the level of difficulty experienced, using a 5-point Likert scale (values ranging from *mild to severe*). Figure 10 displays the level of difficulty ratings for each participant. For all three participants, the level of difficulty experienced while completing the transition-based experimental context was rated in the *severe* range (i.e., ratings of “4” or “5” on the 5-point Likert scale) for 100% of the baseline sessions. For Alana, all of the sessions in baseline were identified as being difficult to complete, and the mean rating of the level of difficulty was 4.6. During intervention, the mean rating of the level of difficulty for the eight sessions that were identified as being difficult to complete was 1.9; thus the mean rating fell within the *mild* range on the 5-point Likert scale). In baseline for Adam, difficulty was noted in all sessions, and the mean rating of the level of difficulty was 4.9. During intervention, eleven sessions were identified as being difficult to complete, and the mean rating of the level of difficulty for these sessions was 2.2; thus, the mean rating fell within the



*moderate* range on the 5-point Likert scale. For Mark, all of the baseline sessions were identified as being difficult to complete, and the mean rating of the level of difficulty was 4.7. During intervention, difficulty was noted in eight sessions, and the mean rating of the level of difficulty was 1.6; thus, the mean rating fell within the *mild* range on the 5-point Likert scale.

#### *Overall Level of Problem Behavior Severity*

Parents were asked to rate the level of severity of the problem behavior exhibited by their child in the transition-based experimental context, using a 5-point Likert scale (values ranging from *mild to severe*). Figure 10 displays parent ratings of the level of problem behavior severity for each participant. Throughout all of the baseline sessions, parents reported that their child demonstrated *severe* levels of problem behavior while participating in their respective problematic activity/routine (i.e., the level of severity was rated either a “4” or “5” on the 5-point Likert scale). For Alana, problem behavior was displayed in all sessions of baseline, and the mean rating of the level of problem behavior severity was 4.8. However, during intervention, problem behavior was demonstrated in only 8 out of 20 sessions, and the mean rating of the level of severity for these sessions was 1.6, which fell within the “mild” range of the Likert scale. For Adam, problem behavior was exhibited in all baseline sessions; the mean rating of the level of problem behavior severity was 4.8. During intervention, however, he displayed problem behavior in 11 out of 17 sessions, and the mean rating of the level of severity for these sessions was 2.1, which fell within the *moderate* range on the 5-point Likert scale. Problem behavior was demonstrated by Mark in all baseline sessions, and the mean rating of the level of problem behavior severity was 4.7. During intervention, he exhibited problem behavior in

7 out of 14 sessions, and the mean rating of severity was 1.4, which fell within the *mild* range of the Likert scale. In sum, following intervention, the number of sessions in which problem behavior was displayed had been substantially reduced for all participants.

#### General Results: Studies 1, 2, and 3

In addition to outcome measures related to latency to problem behavior or latency to successful completion of routines and the various ancillary measures related to side effect intensity, level of difficulty, and problem behavior severity, data were collected, across all three studies to measure global improvement in problem behavior, as well as overall improvements in family quality of life. As noted previously, global measures included the Irritability subscale of the ABC-Community (Aman & Singh, 1994) that measured global perception of the level of severe problem behavior, the Home Situations Questionnaire (Barkley, 1981) that measured the number of home routines negatively impacted by problem behavior, as well as the extent to which the problem behavior disrupted various home routines, the Resident Lifestyle Inventory (Kennedy, Horner, Newton, & Kanda, 1990) that measured family involvement in various community activities and events, and the Parenting Stress Index (Abidin, 1997) that measured the amount of distress experienced by parents. Additionally, we included a supplementary measure, the Developmental Disability Parent Depression/Stress Questionnaire, to assess the level of distress specifically associated with parenting a child with developmental disabilities.

The mean SIAMSE ratings associated with experimental contexts in both baseline and following intervention for each of the nine participants are shown in Table 2. As noted previously, the parents provided ratings of the level of side effect intensity, the

level of difficulty experienced in the priority context, and the level of problem behavior severity, using 5-point Likert scale that ranged from 1 (*mild*) to 5 (*severe*). Across all nine participants, the mean rating of the level of side effect intensity for the experimental context in baseline was 4.56, and the mean rating following intervention was 4.22. A paired sample t-test was used to examine the difference between mean ratings of side effects intensity in baseline versus intervention for the experimental contexts. Ratings of the level of side effect intensity were not significantly different, that is, side effects were still present at elevated levels of intensity in the experimental contexts in baseline and following intervention,  $t(8) = 1.41, p = 0.20$ . The mean rating of the level of difficulty experienced in the experimental context in baseline was 4.67 and the mean rating following intervention was 1.56. Ratings of difficulty were significantly lower following intervention suggesting that the experimental contexts became less difficult for participants to complete following implementation of the intervention,  $t(8) = 15.53, p < 0.05$ . The mean rating of the level of problem behavior severity displayed in the experimental context in baseline was 4.44 and the mean rating following intervention was 1.67. Ratings of problem behavior severity displayed in the experimental contexts were significantly lower suggesting that these priority routines were less likely to be associated with problem behavior following intervention than in baseline,  $t(8) = 18.89, p < 0.05$ .

Paired sample t-tests were also performed on all ancillary measures of global improvements of problem behavior and quality of life to compare scores during baseline with those following intervention. As shown in Table 2, following intervention, there was a significant decrease in the global perception of the level of problem behavior as measured by the Irritability subscale of the ABC-Community,  $t(8) = 4.72, p < 0.05$ .

Additionally, following intervention, there was a significant increase in family involvement in community events and leisure activities as measured by the Resident Lifestyle Inventory,  $t(8) = 6.20, p < 0.05$ . As families were able to engage in more community events, the number of problematic home routines (and the severity of problem behavior in challenging home routines) substantially decreased across all participants. Thus, following intervention, there was a significant decrease in the *number* of problematic routines as measured by the Home Situations Questionnaire,  $t(8) = 4.26, p < 0.05$ . In addition, the *severity* of problem behavior in the problematic home routines was also rated significantly lower following intervention,  $t(8) = 8.21, p < 0.05$ . Finally, following intervention, there was a significant reduction in the amount of stress parents experienced as measured by the Parenting Stress Index-Short Form,  $t(8) = 2.96, p < 0.05$ , as well as by the Developmental Disability Parent Depression/Stress Questionnaire,  $t(8) = 3.55, p < 0.05$ .

The Clinical Global Impressions Scale (CGI) was administered during the post-intervention assessment phase to assess parents' perceptions of overall improvement following intervention (Guy, 1976). Analysis of improvement ratings at post-assessment showed that all nine participants were rated as either *very much improved* or *much improved* (i.e., 1 or 2 on the 7-point Likert scale) on the CGI Improvement scale, as shown in Table. The Global Social Validity Scale (GSVI) was also administered to families following intervention to assess parents' perceptions about the effectiveness of intervention strategies as well as to evaluate the ease of utilizing these procedures to address problem behavior displayed in routines other than those identified as the priority (experimental) contexts. Table 3 displays post-assessment ratings on the three items

comprising the GSVI (i.e., ease of use, ability to be generalized, overall effectiveness), as well as the total scores for each participant. Parents reported that the intervention strategies were *very easy* to use (i.e., ratings of 4 or 5 on question 1 of GSVI) and *often* applied to additional difficult contexts (i.e., ratings of 4 or 5 on question 2 of GSVI). Further, parents of all nine participants rated the overall effectiveness of their respective intervention packages as *very effective* in decreasing problem behavior (i.e., ratings of 4 or 5 on question 3 of GSVI).

### General Discussion

In a series of three studies, the potential impact of medication side effects on the exacerbation of problem behavior exhibited by individuals with developmental disabilities was explored. We examined the possibility that the side effects of psychotropic medications frequently administered to treat severe problem behavior essentially function as setting events in that they negatively impact *certain* home and community activities, paradoxically causing an escalation of the very behaviors the drug was initially prescribed to treat. According to the results obtained during the initial validation and extended baseline phases of the current series of studies, all nine children did in fact experience a variety of medication side effects that parents reported had a negative impact on *particular* family routines. Specifically, observations conducted in the identified (experimental) contexts revealed that when these adverse symptoms were present, they made the specified routines much more difficult for the children to complete, and subsequently led to an increase in the level of problem behavior that was displayed.

Importantly, results obtained in the present series of studies demonstrated that only *certain* activities had become more problematic for the child to successfully complete. That is, none of the parents in our sample reported that all of the home and community routines had become more difficult for their child to complete since going on the most current combination of medication, nor did they indicate that problem behavior increased in all contexts. In other words, the medication regimens that the children were on during the course of the study may have indeed had a beneficial effect on the overall level of problem behavior. However, it was beyond the scope of our study to analyze the efficacy of the medications that were administered to the participants. Our assessments did not include an evaluation of the beneficial effects of the medications, as prior research in the pharmacological field has established this. However, it would be interesting to add a component that examined this aspect of medication intervention in future studies.

In addition to providing a demonstration of the proposed paradoxical effect of medication treatment, the present series of studies evaluated the efficacy of implementing a context-based model of assessment and intervention for severe problem behavior displayed in common routines when medication side effects were present and seemingly functioning as setting events. A comprehensive assessment of problematic activities was conducted, including a thorough examination of the impact that side effects had on the context, as well as the mechanisms involved in evoking problem behavior. Uniquely tailored intervention packages, comprised of mitigation and coping strategies were then developed and implemented to address these problematic family-based activities. Following the implementation of the multicomponent intervention packages, all nine

families were able to engage in and more successfully complete highly valued routines that, prior to treatment, had been extremely problematic due to the presence of medication side effects and problem behavior. Across all participants, the percentage of task steps completed in their respective experimental contexts substantially increased following intervention, and the latency to session termination due to problem behavior was greatly reduced, as families were able to successfully complete their identified routines.

Interestingly, parents reported that the level of intensity of the various drug-induced symptoms experienced by participants did not significantly change over the course of the study. That is, a majority of the medication side effects that were identified in the initial assessment continued to be present at elevated levels of intensity in the experimental contexts throughout all sessions of baseline and intervention. Importantly, following intervention, the *negative impact* of these symptoms did appear to diminish, as evidenced by reductions in parents' ratings of the level of difficulty that was experienced, as well as by substantial reductions in the ratings of the level of severity of problem behavior displayed by all participants in these contexts.

Following intervention, evidence of more global improvements and reductions in problem behavior was noted for all nine participants. Specifically, generalized improvements were reflected by improvements on a number of items on the Structured Interview for Assessment of Medication Side Effects (SIAMSE), including a reduction in the number of activities that parents identified as being "problematic" and associated with problem behavior. Additionally, global reductions in problem behavior were documented across all participants following intervention, as evidenced by improved mean scores on

the Aberrant Behavior Checklist-Irritability Subscale (ABC), as well as by post-intervention assessment ratings of “much improved” and “very much improved” on the Clinical Global Impressions Scale-Global Improvement Subscale (CGI).

Improvements in several dimensions of quality of life were also noted by parents of all nine participants, following implementation of the intervention. Families reported a decrease in both the number of problematic home routines and in the severity of problem behavior associated with these routines (Home Situations Questionnaire), as well as an increase in the number of community activities they were able to participate in upon completion of the study (Residential Lifestyle Inventory). Parents also reported experiencing lower levels of distress, as evidenced by improved mean scores on the Parenting Stress Index (PSI) and on the Developmental Disability Parent Depression/Stress Questionnaire (DDPD/SQ).

*A Context-Based Approach to Assessment and Intervention of Medication Side Effects*

Although a great deal of research has been devoted to determining the effectiveness of the various classes of psychotropic medication to treat problem behavior displayed by individuals with developmental disabilities (Hellings et al., 2005; Kolevzon, Matthewson, & Hollander, 2006; Posey, Puntney, Sasher, Kem, & McDougle, 2004; RUPP, 2002; Shea et al., 2004; Zarcone et al., 2004), the potential impact of some of the more commonly occurring side effects of these medications (e.g., fatigue, increased appetite, agitation) on various family routines has been largely overlooked. Essentially, medication side effects have been *decontextualized* in the literature, despite the mounting evidence of the significant role of context as an influence on problem behavior (Luiselli & Cameron, 1998; McAtee, Carr, & Schulte, 2004). As a result, potentially valuable



information about these side effects may not be included nor effectively utilized in the assessment and intervention processes.

Traditionally, drug side effects have been dealt with in several ways including: altering the dosage of the medication, discontinuing the drug, or by prescribing an additional medication that targets the side effect. Not surprisingly, each of these methods, commonly used in clinical practice, has certain disadvantages. For example, if a medication is producing an undesirable side effect, a physician may lower the dosage of the drug. However, a disadvantage of this approach may be a reduction in the effectiveness of the medication in reducing the targeted problem behavior (i.e., the intended beneficial effects). An alternative method commonly employed to address side effects is to discontinue the medication. Although this approach would likely reduce the undesirable symptoms, the beneficial effects of the drug would most likely be eliminated as well. Finally, the side effects may be addressed by administering an additional drug targeting the adverse symptoms. However, as noted previously, most medications are associated with an array of side effects (PDR, 2004), thus, when new drugs are added, they may produce new problematic symptoms that then, in turn, require treatment.

Given the difficulties noted in using a purely pharmacological model to deal with drug side effects, investigators may wish to explore the potential efficacy of utilizing a context-based approach to assessment and intervention of problem behavior associated with medication side effects. Clearly, parallels exist between the various contextual variables (i.e., setting events) that have been documented in the behavioral literature and the array of symptoms that are most often noted in the pharmacological literature as common side effects of psychotropic medication. As noted previously, a considerable

amount of evidence exists documenting the association between setting events such as fatigue, illness, and discomfort and the subsequent occurrence of severe problem behavior (Carr et al., 2003; Kennedy & Meyer, 1996; O'Reilly, 1997; Symons, Davis, & Thompson, 2000; Wiggs & Stores, 1996). Numerous studies have demonstrated that when individuals with developmental disabilities experience elevated levels of discomfort associated with menses, allergies, or gastrointestinal ailments, they are more likely to engage in elevated levels of problem behavior when presented with task demands (Bosch, Van Dyke, Milligan Smith, & Poutlton, 1997; Carr et al., 2003; Kennedy & Meyer, 1996). The presence of discomfort operates as a setting event, subsequently enhancing the aversiveness of certain tasks, thereby increasing the likelihood that an individual will display problem behavior in order to escape or avoid these situations. Thus, it would seem plausible that medication side effects may function in much the same manner as biological setting events in altering an individual's response to a given environmental context, and, in turn, increasing the likelihood of problem behavior. Therefore, it would seem logical to approach the assessment and intervention of these adverse symptoms utilizing the same methods that have been found to effectively reduce problem behavior associated with setting events. That is, it may be beneficial to conceptualize medication side effects as biological setting events to enhance our understanding of the mechanisms involved in evoking problem behavior, thereby improving our ability to design multicomponent intervention packages that ultimately yield positive and enduring outcomes for families.

To illustrate the possible mechanisms by which medication side effects may function as setting events for problem behavior in commonly occurring family routines, we will examine the behavior of one participant from each of the three studies.

*Study 1-Home-Based Routines: Robby (Household Chores Routine)*

Recall that Robby's mother and grandmother reported that since he had gone on the most current combination of medication, they noticed that he experienced elevated levels of fatigue, increased irritability and agitation, as well as more frequent episodes of haziness/difficulty concentrating following the administration of the medication. According to his mother, when these symptoms were present, Robby tended to experience greater difficulty completing the daily household chores routine, and, consequently, she noted that he was much more likely to engage in severe problem behavior (e.g., aggression, self-injury, tantrum behavior). Therefore, the medication side effects were plausibly functioning as setting events for Robby's problem behavior. That is, these symptoms acted as variables that increased the aversiveness of the activity (i.e., household chores), and when present, they made it much more difficult for him to participate in the routine, thereby strengthening any behavior that reliably allowed Robby to escape from having to comply with the demand. In other words, Robby's problem behavior was negatively reinforced (i.e. demands were removed or the task was delayed) to a greater degree when these side effects (i.e., setting events) were present than when they were not.

Given the aversiveness of the household chores routine when the side effects were present, it was logical to employ several mitigation strategies to modify various aspects of the routine to reduce some of the difficulty Robby experienced. Specifically, we

altered the time of day that the routine was scheduled, and arranged for him to complete this activity several hours after taking his medication to reduce the likelihood that the medication-induced fatigue and episodes of haziness were present. Additionally, a visual schedule, depicting the sequence of steps comprising the routine was created to make the activity easier and more predictable for Robby, hence reducing or preventing the problem behavior. Furthermore, Robby's intervention package included a coping strategy that involved teaching him how to more appropriately request assistance (i.e., Robby was prompted to say "help me") when experiencing difficulty due to side effects while completing his chores in lieu of aggression and tantrums.

*Study 2-Community-Based Routines: Ellie (Grocery Store Routine)*

Recall that Ellie's mother reported that she experienced a variety of medication side effects including marked fatigue, irritability/agitation, and significantly increased hunger following administration of her current medication regimen. According to her mother, when these symptoms were present, they seemed to make the grocery store routine much more difficult for Ellie, and it turn, she was much more likely to engage in severe problem behavior (e.g., aggression, self-injury, property destruction) than was the case prior to going on the current dosages of the medications. Thus, fatigue presumably functioned as a setting event for Ellie's problem behavior in this context. That is, when present, the drug-induced fatigue caused her physical discomfort and increased the aversiveness of the activity, thereby strengthening any behavior that reliably allowed her to escape having to comply with demands placed on her during this routine. Therefore, Ellie's problem behavior was negatively reinforced to a greater degree when setting events (i.e. drug-induced fatigue) was present than when it was not.

Additionally, her mother stated that since going on the medication, Ellie's appetite had substantially increased and she had gained a noticeable amount of weight in the past several months. She stated that Ellie was continually attempting to gain access to food throughout the day and that she often displayed severe tantrum behavior when she was told to "wait" or was denied access to a desired food item. Accordingly, being in the grocery store became exceedingly problematic, as Ellie's increased hunger interfered with her ability to complete the routine without engaging in problem behavior that functioned to gain access to desired items (i.e. food). Therefore, excessive hunger also plausibly served as a setting event for Ellie's problem behavior in this context. That is, hunger was a variable that increased the aversiveness of the demands related to the activity, thereby strengthening any behavior that allowed Ellie to escape from having to comply with the demands. In addition, experiencing elevated levels of hunger also enhanced the reinforcing potential of food that was readily accessible at the grocery store, making it much more likely that Ellie would engage in problem behavior in order to gain access to food items she desired.

Given the aversiveness of this activity within the context of increased fatigue and hunger, it was logical to implement several mitigation strategies to reduce some of the difficulty Ellie experienced when these side effects were present. A neutralizing routine was used to address difficulties related to increased hunger. Ellie was provided with free access to several highly preferred snack items that she could eat while she appropriately completed the shopping routine. Thus, providing access to desired items of food while shopping presumably reduced some of the aversiveness experienced during the activity and undermined the necessity for escape-motivated problem behavior. A visual schedule

that outlined the sequence of steps involved in the activity was implemented to make the routine more predictable and reduce some of the difficulty she experienced when side effects were present. Additionally, a coping strategy was included in the intervention package that taught Ellie a more appropriate method to manage difficulties associated with having to wait while participating in the grocery store routine. Specifically, Ellie was taught to use a deep breathing exercise to help reduce some of the distress she experienced when side effects were present, thereby reducing the likelihood of problem behavior.

*Study 3-Transition-Based Routines: Mark (Transitioning During Community Outings)*

Recall that Mark's parents reported that since going on the most current dosages of his medication regimen, experienced a variety of side effects, most notably, elevated levels of fatigue, episodes of increased haziness, and more frequent bouts of gastrointestinal discomfort and diarrhea. They stated that the presence of these symptoms made common community activities much more difficult for Mark to complete, and consequently, he was much more likely to display severe problem behavior (e.g., tantrums, aggression, property destruction) than was the case prior to starting the current regimen of medication. Specifically, they stated that transitioning between locations during outings in the community became much more problematic for Mark on days when he was noticeably more lethargic and experiencing episodes of haziness (following medication administration). Further, they noted that he more frequently suffered from bouts of diarrhea, accompanied by stomach cramps and discomfort. These physical symptoms greatly reduced his tolerance for demands, and made transitioning even more difficult than it had been prior to going on the current combination of medication, and, in

turn, he was much more likely to engage in severe problem behavior. Thus, these side effects plausibly operated as setting events for Mark's problem behavior. That is, these symptoms increased the aversiveness of the demands involved in transitioning (i.e., ending one activity and physically having to move to another location), thereby strengthening any behavior that reliably allowed Mark to escape having to comply with demands placed on him during this context. Hence, Mark's problem behavior was negatively reinforced to a greater extent when these side effects were present than when they were not.

Given the aversiveness of having to transition between locations during community outings when side effects were present, it was logical to employ several mitigation strategies to modify aspects of the routine to reduce some of the difficulty Mark experienced. A visual schedule depicting the sequence of steps that comprised the routine was created and to make the transition-based activity more predictable for Mark. Additionally, to help him more effectively cope with increased agitation as well as with gastrointestinal discomfort that he experienced following administration of his medication, we included a coping skill strategy in the intervention package. Specifically, Mark was taught to use a relaxation technique (i.e., a deep breathing exercise) to help attenuate some of the distress he experienced during the transition when side effects were present, thereby reducing the likelihood of problem behavior.

#### *Implications of a Context-Based Approach to Assessment and Intervention of Side Effects*

The outcome of the present series of studies supports previous research demonstrating the effectiveness of using a context-based approach for reducing problem behavior and enhancing family quality of life (Carr et al., 2003; Gardner, Cole, Davidson,

& Karan, 1986). Additionally, these studies serve to highlight the benefits of conducting a comprehensive and “contextualized” analysis of medication side effects in order to determine the potential *impact* that these symptoms may have in relation to the broader context in which they occur. Essentially, when medication side effects are conceptualized as operating as biological setting events, the mechanisms involved in evoking problem behavior can be more clearly identified, thereby resulting in the development of intervention packages that more effectively reduce problem behavior by mitigating problematic aspects of certain contexts as well as by teaching the individual alternative and appropriate ways to cope with difficulties encountered when side effects are present.

If the side effects of psychotropic medications are indeed functioning as setting events, as suggested by the results of the present series of studies, then it might be beneficial to use a *combination* of pharmacological and behavioral approaches, whereby the drugs would target the problem behavior and behavioral interventions would be used to manage the difficulties related to the side effects. The rationale behind the combination approach is as follows: Drugs often do have an impact on problem behavior; however, the side effects may interfere with a positive outcome because they function as setting events for subsequent problem behavior, thereby obscuring the primary impact of the drug. Behavioral procedures can help minimize the side effects (setting events), so that the primary effect of the drug is no longer compromised by the presence of these symptoms. Interestingly, combining the behavioral and pharmacological treatments may enhance the efficacy of the drug in reducing problem behavior. Precedents exist in the ADHD and depression literatures for combining various methods of intervention (behavioral and pharmacological treatments), in order to design a comprehensive



treatment package that has been empirically shown to be more effective than either treatment alone (Barkley, 1990; Bernstein et al., 2000; Carlson, Pelham, Milich & Dixon, 1992; Conners et al., 2001; Keller et al., 2000; MTA Cooperative Group, 1999). For example, results from a study conducted by Pelham, Schnelder, Bologna, and Contreras (1980) suggest that the combination of psychostimulant medication and behavioral intervention may be more effective than either treatment alone for children with ADHD in school settings. Likewise, using a combination of medication and behavioral intervention for depression has been found to be more effective than either treatment alone (Keller et al., 2001). Plausibly, the same may be true for problem behavior in developmental disabilities, thus, suggesting that researchers and clinicians in both disciplines may wish devote their efforts toward greater collaboration, and adopt a multimodal approach to treatment of problem behavior associated with autism.

In sum, a model that conceptualizes drug side effects as setting events for problem behavior may improve or preserve the overall effectiveness of medication, while eliminating or reducing problem behavior. This conceptualization has direct implications for furthering programmatic research on assessment and intervention, thereby enhancing our understanding of problem behavior and potentially increasing the number of intervention options relevant to addressing this clinically important issue.

#### *Ecological and Social Validity*

A great deal of research on the assessment and intervention of problem behavior has involved the use of controlled laboratory and analog situations that simulate aspects of more natural environments (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982). This line of research has played a pivotal role in documenting the factors involved in

producing problem behavior, as well as in providing key guidelines for developing effective intervention strategies. However, critical questions remain regarding the applicability of information generated from these rigorously controlled settings to more naturalistic environments (Carr et al., 2002). The data produced across the present series of studies suggest that context-based strategies are robust with respect to multiple key aspects of ecological validity. Specifically, the strategies were reportedly found to be easy to use in natural settings (e.g., the home, grocery store, doctor's office), and were implemented by natural intervention agents (e.g., parents) within naturally occurring activities (e.g., completing household chores, eating dinner, doing homework).

The clinical significance (i.e., social validity) of intervention strategies is an important factor to consider when working with families (Wolf, 1978). The results of the quality of life measures that were obtained in the final phase of the present series of studies suggest that parents noted a broad range of intervention effects in important aspects of their daily lives. Specifically, parents reported improvements with respect to participation in community activities, behavior during home routines (in addition to the priority context), and overall level of parental distress. Further, there were improvements with respect to parental sense of control over their child's behavior and in their ability to more effectively manage side effects of medication to reduce their impact and prevent problem behavior despite the continued presence of these symptoms. Importantly, these improvements were clinically significant for families in that upon completion of the study, they rated their daily experiences more positively.

### *Concluding Comment*

It is anticipated that the current series of studies will engender a line of programmatic research that will continue to systematically investigate the potential impact that medication side effects may have on problem behavior, as well as highlight the significant treatment implications arising from conceptualizing these commonly occurring symptoms as setting events for problem behavior. Essentially, results from this study serve to substantiate the importance of *re-contextualizing* drug side effects in order to provide families and clinicians with a more comprehensive understanding of the variables that control problem behavior to ultimately help them design more meaningful and efficacious interventions that bridge the gap between the behavioral and pharmacological fields to reduce problem behavior and enhance family quality of life.

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## Appendix A

### Structured Interview for Assessment of Medication Side Effects (SIAMSE)

#### A. Demographics

1. Your Name: \_\_\_\_\_ Date: \_\_\_\_\_
2. Address: \_\_\_\_\_ Phone: \_\_\_\_\_
3. Relationship to Child (e.g. mother, father, guardian, etc.): \_\_\_\_\_
4. Child's Name: \_\_\_\_\_ Child's Age: \_\_\_\_\_ Child's Sex (circle one): M F
5. Child's Diagnosis \_\_\_\_\_
6. Please list any chronic health problems that your child has (e.g. asthma, diabetes, seizures, etc.) \_\_\_\_\_
7. Is your child able to communicate with you through speech, sign language, PECs, or another Augmentative Communication Device (Please describe)? \_\_\_\_\_

#### B. Medication History

1. Is your child presently on medication for problem behavior (i.e. for a period of at least two weeks)?  
Circle one: YES NO
2. Is your child *currently experiencing* adverse side effects while on medication for problem behavior?  
Circle one: YES NO
3. What type of problem behavior led to your child being put on medication?  
(Circle all that apply on attached **Problem Behavior Table**)  
Please describe: \_\_\_\_\_
4. For *each* medication (or combination of medications) that your child is currently on, and/ or has been on in the **last 12 months** please provide the following information (beginning with the most recent and working backwards):
  - a. Name of medication: \_\_\_\_\_ b. Date started: \_\_\_\_\_
  - c. Dosage level: Initial: \_\_\_\_\_ Current: \_\_\_\_\_
  - d. Type of problem behavior currently being treated by the medication: \_\_\_\_\_
  - e. How many times per day is the medication given (e.g., 3 times a day)? \_\_\_\_\_
  - f. What time of day is the medication given (e.g., before meals)? \_\_\_\_\_
5. For *each* medication listed in Question 4, please answer the following questions:
  - a. After the medication was started, did your doctor **change the dosage level**?  
Circle one: YES NO
  - b. Why did your doctor **change the dosage level**? Check **ALL** that apply:
    - i. \_\_\_\_\_ My child experienced acute negative side effects (physiological, motor, cognitive, affective)
    - ii. \_\_\_\_\_ My child's problem behavior got worse (new/different problem behavior was exhibited)
    - iii. \_\_\_\_\_ My child's problem behavior did not decrease
    - iv. \_\_\_\_\_ My child's problem behavior did not decrease to a satisfactory level
    - v. \_\_\_\_\_ My child's problem behavior improved and he/she required less medication
    - vi. \_\_\_\_\_ Other (please specify)
  - c. Was the dosage level increased or decreased? (Please specify): \_\_\_\_\_

**C. Nature of Side Effects**

For each medication identified in question 5 of Part B (i.e., dosage change), please answer the following:

- 1. What are the current side effects of the medication(s) he/she is receiving? (Please circle all that apply on the attached **Side Effects Table**)

**For each side effect identified:**

2. How do you know when your child is experiencing this side effect (i.e. what does he/she do/say/look like when the side effect is present)? \_\_\_\_\_

3. How frequently (number of days per week), on the average, is the side effect present? \_\_\_\_\_

4. When your child is experiencing the side effect, how long, on the average, does the side effect episode last (how many minutes or how many hours)? \_\_\_\_\_

5. When your child is experiencing the side effect, how intense is it, on the average, using the following scale:

Mild	Moderate	Severe			
1	2	3	4	5	

6. For each side effect (e.g., fatigue) you identified, specify whether the overall level (i.e., frequency, duration, and intensity combined) of the symptom described (i.e., fatigue) is now slightly worse, somewhat worse, or much worse than what it was **before** your child went on medication. Alternatively, you may indicate that the current overall level of symptoms is the same as it was before the medication.

Slightly Worse	Somewhat Worse	Much Worse	Same	
1	2	3	4	5 X

- 7. Have other people mentioned/commented on the presence of side effects?

Circle one: Yes No

If so, who? Teacher/Friend/Neighbor/Other relative \_\_\_\_\_ Other person \_\_\_\_\_

**D. Impact on Context**

1. Since your child has gone on medication, is he/she having more difficulty with any activities at home or in the community?

Circle one: Yes No

2. If you answered “Yes,” then specify which activities. (Please circle all that apply on the attached **Activities Table**).

3. During the activities you specified, have you noticed the presence of any of the medication side effects you mentioned earlier?

Circle one: Yes No

4. If you answered “Yes,” then specify which side effect(s) was (were) present that made each activity more difficult: \_\_\_\_\_

5. If you answered “Yes” to Question 3, please specify whether the presence of the side effect (described in Question 4) has made successful completion of each activity slightly more difficult, somewhat more difficult, or much more difficult than was the case **before** your child went on medication. You may also circle No Impact if that was the case.

Slightly More Difficult		Somewhat More Difficult		Much More Difficult	No Impact
1	2	3	4	5	X

**E. Impact on Problem Behavior:**

1. For *each* activity you identified in Part D (question 5), in which the activity became more difficult because of the presence of side effects, please specify whether your child sometimes shows problem behavior during the activity.

Circle one: Yes No

Type of problem behavior(s) (Please refer to **Problem Behavior Table**):

---

**\*2. If you answered “Yes,” then specify whether the level of problem behavior during the activity is slightly greater, somewhat greater, or much greater since your child has been on the medication, as compared to before he/she was placed on the medication. You can also circle No Change if that was the case.**

Slightly Greater	Somewhat Greater	Much Greater	No Change	Less
1	2	3	4	5
			X	Y

3. If you answered “Greater” (ratings between 1-5), please describe the type of problem behavior, and indicate if this is an increase in an existing problem behavior (i.e. behavior that the medication was intended to treat), or a new type of problem behavior.

A. Is this an increase in an EXISTING problem behavior?

Circle one: Yes No

B. Is this a NEW type of problem behavior?

Circle one: Yes No

**F. Impact on Motivation/Consequences:**

1. When your child displays problem behavior while experiencing a side effect during an activity, describe how you or other members of your family respond to the behavior. What do you say? What do you do (e.g. Do you change how you carry out the activity)? Do you discontinue the activity? \_\_\_\_\_

2. Do you now try to avoid the activity more so than was previously the case?

Circle one: Yes No

## PROBLEM BEHAVIOR TABLE

### **Aggression/Irritability:**

Physically hurts others - hits, kicks, pinches, bites, head butts, punches, scratches, pull's hair, pokes eyes, spits

Verbally aggresses toward others - curses, insults, threatens, "talks back," verbally "nasty"

Destroys property - angrily breaks, rips, tears objects.

Other (please specify)

### **Self-injury:**

Hits head, bangs head on walls or other objects, bites hands, slaps or punches own face, pinches self, pulls out own hair, picks at skin/scab until it bleeds

Other (please specify)

### **Tantrum behavior:**

Angry crying/screaming, stomping around/throwing self on floor/ thrashing body around

Other (please specify)

### **Noncompliance:**

Task refusal; pushes away work materials; runs away from adults/peers; falls to floor and refuses to move when requested; whining/complaining

Other (please specify)

### **Repetitive behavior:**

Self-stimulatory behavior/repetitive motor movements (e.g., body rocking, hand flapping); stereotypy;

Repetitive speech, obsessive speech

Compulsive/ritualistic behaviors, tics

Other (please specify)

### **Depressive features/Mood disturbances:**

Depressed mood/sadness/crying/weepy, withdrawn, moody, "no personality," overly sensitive,

Mood changes/swings, excessive elation/manic episodes

Other (please specify)

### **Anxious/obsessive traits:**

Excessive worry/anxiety/fearful; intrusive thoughts; obsessive thoughts

Other (please specify)

### **Hyperactivity/Attention difficulties:**

Overactive/impulsive/fidgeting, difficulty concentrating, off-task behavior

Short attention span, easily distracted

Other (please specify)

### **Disruptive Behavior:**

Yelling, making weird noises, acting silly

Other (please specify)

### **Sleep Disturbances:**

Insomnia, difficulty falling/staying asleep, excessive sleep

Other (please specify)

### **Other types of problem behavior :**



## SIDE EFFECTS TABLE

### PHYSIOLOGICAL:

#### Sleep problems

- onset/trouble falling asleep
- night awakenings
- early awakenings
- too much sleep
- nightmares
- night terrors
- daytime sleepiness/drowsiness

#### Fatigue/lethargy

#### Eating problems

- weight gain (\_\_\_\_ lbs)
- weight loss (\_\_\_\_ lbs)
- appetite increase
- appetite decrease
- binging (driven eating)
- driven quality to drinking/excessive thirst
- dry mouth

#### Vision problems

- blurred vision
- watery eyes
- red /itchy eyes

#### Headache

#### Dizziness

#### Fainting

#### Seizure

#### Fever/flushed

#### Sweating

### MOTOR:

#### Clumsiness/awkward movements

#### Slurred speech

#### Stuttering

#### Fine motor impairments

#### Tardive dyskinesia/jerky movements

#### Tics/twitching

#### Rigidity in muscle tone

#### Repetitive motor behavior (new behavior or increase in old behavior)

#### OTHER (please specify)

### COGNITIVE:

#### Difficulty concentrating/paying attention

#### Confusion/loss of orientation/delirium

#### Difficulty with memory/memory loss

#### Latency to speak (speech hesitancy)

#### OTHER (please specify)

### AFFECTIVE:

#### Irritable/agitated/jittery/jumpy

#### Inappropriate affect/laughing/silly

#### Mood swings/emotional lability

#### Sadness/crying spells/feelings easily hurt/seems depressed

#### Intrusive/obsessive thoughts/compulsive behaviors (e.g. finger picking)

#### OTHER (please specify)

#### Urinary problems

- nighttime bedwetting
- daytime bedwetting
- bowel accidents/encopresis
- increased urge to urinate
- decreased urge to urinate
- painful urination

#### Gastrointestinal problems

- abdominal pain
- nausea
- vomiting/retching
- diarrhea
- constipation
- bloating

#### Sexual/reproductive side effects

- orgasmic/masturbatory problems
- amenorrhea/irregular/painful periods
- hypersexual behavior

#### Itchy skin/rash/infection

#### Nasal Congestion/running nose

#### Breathing problems

#### OTHER (please specify)

#### Drooling

#### Lack of coordination

#### Difficulty walking

#### Overactivity

#### Restlessness

#### Tremors/shakiness

#### Loss of muscle tone

#### Spaciness/haziness

#### Hallucinations (visual/auditory)

#### Word finding problems

#### Less speech output

#### Anxious/fearful/worried

#### Anhedonia/loss of interest

#### Blunted/flat affect

## Home & Community Activities/Routines

### Home Activities:

Waking up/getting out of bed  
Brushing teeth  
Showering/bathing  
Grooming (comb hair, etc.)  
Getting dressed  
Eating breakfast (preparing breakfast)  
Talking with parents  
Getting to bus stop/on bus  
Practicing instrument/karate/dance etc.  
Playing by oneself – (reading, t.v., computer)  
OTHER (please specify)

Eating/preparing lunch  
Getting/eating snack  
Doing homework  
Chores (cleaning house, room, etc.,)  
Playing with siblings/friends/pets  
Setting table/clearing table/helping at dinner  
Sitting down at table/eating dinner  
Preparing for bed/going to sleep  
Getting ready for community activity

### Community Activities:

Supermarket  
Movies/museum/library  
Mall/shopping  
Parents' office/place of work  
Local park  
Car/train/bus/plane rides  
Sports: team and individual  
(e.g., soccer, bowling, mini-golf)  
Relatives' houses/family gatherings  
OTHER (please specify)

Friends/peers' houses (play dates)  
Amusement park  
Restaurants  
Lessons (e.g., music, dance, karate, etc.)  
Doctors' offices  
Religious services  
Special entertainment (e.g., concerts,  
professional sports)  
Vacations

Appendix B

**Follow-up Questions**

(adapted from O'Neill et al., 1997)

(1) What are the *specific tasks or steps* that are involved in the activity/routine are you referring to? \_\_\_\_\_  
\_\_\_\_\_

(2) With *whom* is problem behavior most likely to occur? \_\_\_\_\_  
\_\_\_\_\_

(3) In what *setting* is problem behavior most likely to occur? \_\_\_\_\_  
\_\_\_\_\_

(4) During what *time of day* is problem behavior most likely to occur? \_\_\_\_\_  
\_\_\_\_\_

(5) What is your *response* to problem behavior? \_\_\_\_\_  
\_\_\_\_\_

(6) What is your *child's reaction*? \_\_\_\_\_  
\_\_\_\_\_

## Appendix C

### **Problem Solving Template**

(adapted from Stiebel, 1999)

1. Identifying the problematic activity/routine.
2. Identifying possible reasons for problem behavior in that activity/routine.
3. Brainstorming solutions.
4. Discussing pros and cons of each solution.
5. Selecting the solution that fits best with the routine of interest.
6. Planning a strategy for implementing the solution.
7. Reviewing key questions relevant to the solution:
  - a. What are the family goals for the routine?
  - b. Do the solutions support your goals for the routine?
  - c. Will the solutions work over an extended period of time (6-12 months)?
  - d. Are you comfortable with what you'll be doing?
8. Planning a follow-up meeting to discuss progress and to troubleshoot.

Appendix D

**Components and Rationale for Interventions Used in Each Context**

<b>Participant</b>	<b>Context</b>	<b>Intervention Strategy</b>	<b>Rationale</b>
Alexa	Mealttime Routine*	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Advanced verbal warnings	To enhance predictability and help child prepare for transition, end of an activity, or upcoming disliked routine
		Embedding	To introduce preferred stimuli into problematic context
		Functional Communication Training	To teach a more appropriate form of communication to replace maladaptive behavior
		Teach relaxation strategies	To help child recognize signs of anxiety and develop effective ways to cope
	Grooming Routine	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Providing assistance	To provide additional support and prompts during difficult activities
	Homework Routine	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Providing assistance	To provide additional support and prompts during difficult activities
	Scott	Homework Routine*	Visual schedule
Modifying the routine			To provide shorter tasks that are more manageable, less aversive
Embedding			To introduce preferred stimuli into problematic context
Advanced verbal warnings			To enhance predictability and alert child of time until difficult task ends
Functional Communication Training			To teach a more appropriate form of communication to replace maladaptive behavior
Teach relaxation strategies			To help child recognize signs of anxiety and develop effective ways to cope
Mealttime Routine		Choice making opportunities	To motivate child to complete routines by incorporating preferences
Playing with Sibling		Visual schedule	To show sequence of steps in routine and enhance predictability
Bedtime Routine		Positive bedtime routines	To establish consistent bedtime routine, increase predictability, prepare for sleep

Note: Asterisks denote “experimental” problem contexts. All other contexts shown constitute the “clinical extension.”

cont.

<b>Participant</b>	<b>Context</b>	<b>Intervention Strategy</b>	<b>Rationale</b>
Robby	Household Chores*	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Modifying the routine	To provide shorter tasks that are more manageable, less aversive
		Behavior momentum	Effects of high rate of reinforcement for easier tasks will carry over to motivate child to complete nonpreferred tasks
		Providing opportunities for making choices	To motivate child to complete routines by incorporating preferences
		Functional Communication Training	To teach a more appropriate form of communication to replace maladaptive behavior
		Teach relaxation strategies	To help child recognize signs of anxiety and develop effective ways to cope
	Transitions	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Choice of reinforcer	To provide opportunity to choose preferred item child can access upon completing difficult routine to enhance motivation
	Grooming Routine	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Choice of reinforcer	To provide opportunity to choose preferred item child can access upon completing difficult routine to enhance motivation

Note: Asterisks denote “experimental” problem contexts. All other contexts shown constitute the “clinical extension.”

cont.

<b>Participant</b>	<b>Context</b>	<b>Intervention Strategy</b>	<b>Rationale</b>
Jack	Restaurant*	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Visual representation time	To enhance predictability by showing child when activity will occur
		Advanced verbal warnings	To enhance predictability and alert child of time until difficult task ends
		Embedding	To introduce preferred stimuli into problematic context
		Functional Communication Training	To teach appropriate form of communication to replace maladaptive behavior
		Choice making opportunities	To motivate child to complete routines by incorporating preferences
	Shopping	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Neutralizing routine	To introduce stimuli associated with appropriate behavior prior to presenting difficult task
	Household Chores Routine	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
Ellie	Grocery Store*	Modifying the routine	Altered time difficult activity was presented to reduce aversiveness
		Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Neutralizing routine	To introduce stimuli associated with appropriate behavior prior to presenting difficult task
		Teach relaxation strategies	To help child recognize signs of anxiety and develop effective ways to cope
		Functional Communication Training	To teach appropriate form of communication to replace maladaptive behavior
	Brushing Teeth	Modifying the routine	To provide additional support and prompts during difficult activities
		Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Advanced verbal warnings	To enhance predictability and alert child of upcoming disliked activity
	Household Chores Routine	Modifying routine	To provide additional support and prompts
		Visual schedule	To show upcoming activities or sequence of steps in routine; enhance predictability
		Advanced verbal warnings	To enhance predictability; alert child of upcoming disliked activity
	Bedtime Routine	Advanced verbal warnings Positive bedtime routines	To enhance predictability; alert child of upcoming disliked routine, preferred activity To establish consistent bedtime routine, increase predictability, prepare for sleep

Note: Asterisks denote “experimental” problem contexts. All other contexts shown constitute the “clinical extension.”

cont.

<b>Participant</b>	<b>Context</b>	<b>Intervention Strategy</b>	<b>Rationale</b>
Neil	Doctor Appointment*	Social Story	To provide predictability about what will occur at appointment
		Visual representation of time (timer)	To show time remaining in disliked activity
		Neutralizing routine	To introduce stimuli associated with appropriate behavior prior to presenting difficult task
		Choice of activity reinforcer	To motivate child to complete difficult routine in order to gain access to preferred activity/item upon completion
		Teach relaxation strategies	To help child recognize signs of anxiety and develop effective ways to cope
	Household Chores Routine	Social Story	To provide predictability about what will occur at appointment
	Transitions	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability

Note: Asterisks denote “experimental” problem contexts. All other contexts shown constitute the “clinical extension.”

cont.



<b>Participant</b>	<b>Context</b>	<b>Intervention Strategy</b>	<b>Rationale</b>	
Alana	Transitioning to/from car*	Visual schedule	To show sequence of steps in routine and enhance predictability	
		Visual representation time	To show time remaining	
		Advanced verbal warnings	To enhance predictability; alert of upcoming disliked routine, end preferred activity	
		Transition item	To provide child with motivation	
		Choice	To motivate child to complete difficult routine to gain access to preferred activity	
		Teach self-regulation skills	To teach skills to help child become more alert/engaged, cope with side effects	
	Getting Dressed Routine	Visual schedule	To show sequence of steps in routine to enhance predictability	
		Choice	To motivate child to complete difficult routine to gain access to preferred activity	
	Restaurants	Visual schedule	To show sequence of steps in routine to enhance predictability	
		Choice	To motivate child to complete difficult routine to gain access to preferred activity	
	Grooming Routine	Visual schedule	To show sequence of steps in routine and enhance predictability	
		Choice	To motivate child to complete difficult routine	
	Adam	Morning transition to school*	Visual schedule	To show sequence of steps in routine to enhance predictability
			Visual representation time	To show time remaining
Advanced verbal warnings			To enhance predictability; alert of upcoming routine/end of preferred	
Providing access to preferred item			To introduce discriminative stimulus associated with appropriate behavior	
Functional Communication Training			To teach appropriate form of communication to replace maladaptive behavior	
Choice			To motivate child to complete difficult routine to gain access to preferred activity upon completion	
Teach relaxation strategies			To help recognize signs of anxiety	
Household Chores Routine		Visual schedule	To show upcoming activities to enhance predictability	
		Modifying the routine	To provide additional prompts	
Shopping Routine		Visual schedule	To show upcoming activities and enhance predictability	
	Visual representation time	To enhance predictability		

Note: Asterisks denote “experimental” problem contexts. All other contexts shown constitute the “clinical extension.”

cont.

<b>Participant</b>	<b>Context</b>	<b>Intervention Strategy</b>	<b>Rationale</b>
Mark	Transitioning during community outings*	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Choice of reinforcer	To motivate child to complete difficult routine to gain access to preferred activity upon completion
		Video Self-Modeling	To teach adaptive skills by embedding instruction within preferred activity (watching TV)
		Neutralizing routine	To introduce stimuli associated with appropriate behavior prior to presenting difficult task
		Teach relaxation strategies	To help child recognize signs of anxiety and develop effective ways to cope
	Household Chores Routine	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Choice	To motivate child to complete difficult routine in order to gain access to preferred activity/item
		Neutralizing routine	To introduce stimuli associated with appropriate behavior prior to presenting difficult task
		Modifying the routine	To provide additional support and prompts during difficult activities; shorten tasks
	Shopping Routine	Visual schedule	To show upcoming activities or sequence of steps in routine and enhance predictability
		Choice	To motivate child to complete difficult routine in order to gain access to preferred activity/item
		Neutralizing routine	To introduce stimuli associated with appropriate behavior prior to presenting difficult task
		Modifying the routine	To provide additional support and prompts during difficult activities
	Restaurants	Visual schedule	To show sequence of steps in routine and enhance predictability
		Choice	To motivate child to complete difficult routine in order to gain access to preferred activity/item
Modifying the routine		To provide additional support and prompts during difficult activities	

Note: Asterisks denote “experimental” problem contexts. All other contexts shown constitute the “clinical extension.”

cont.

## Appendix E

### Decision Tree for Intervention Protocol

1. Administer SIAMSE and assessment measures
2. Family identifies *the* most difficult activity/routine (highest priority) as the experimental context
3. Families are taught how to implement the various components of the intervention package for the experimental context; 1-2 teaching sessions conducted with each family between the baseline and intervention phases.
4. Family must run three intervention sessions independently of researcher. At session 4, has the family mastered interventions for the experimental context (based on direct observation conducted by 2 raters and the Intervention Integrity Checklist)?
  - a. If YES → family was provided with intervention strategies for clinical extension contexts
  - b. If NO → the family was provided with additional training for another session. Step 4 was repeated.

**Experimental Context Parent Ratings Form**

**Rater:** \_\_\_\_\_ **Relation to Child:** \_\_\_\_\_  
**Activity/Routine (Experimental Context):** \_\_\_\_\_  
**Side Effect(s):** \_\_\_\_\_  
**Problem Behavior(s):** \_\_\_\_\_

Please provide the following ratings *each* time your child engages in the identified problematic activity/routine. Record your ratings in the attached tables. Descriptions of terms are provided below.

**1. Start time of activity/routine:** \_\_\_\_\_ **End time:** \_\_\_\_\_

**2. Latency to session termination:** \_\_\_\_\_  
 (The amount of time that elapsed before the session was terminated due to problem behavior or successful completion of the activity).

**3. Number of steps in activity/routine completed:** \_\_\_\_\_

**4. Reason for session termination:** \_\_\_\_\_  
 (1 instance of intolerated problem behavior; 3 instances of tolerated problem behavior; or successful completion of activity)

**5. Are side effect(s) present in the identified activity/routine today?**

Yes                      No

**6. Side Effect Level of Intensity Rating:**  
 When your child is experiencing the side effect(s) today during the specified routine, how intense is it (are they), on the average, using the following scale:

Mild		Moderate		Severe
1	2	3	4	5

**7. Routine Difficulty:**  
 Is the routine difficult for your child to successfully complete **today**?

Yes                      No

**8. Routine Difficulty Rating:**  
 When the routine is more difficult for your child to successfully complete, please rate the level of difficult experienced using the following scale:

Mild		Moderate		Severe
1	2	3	4	5

**9. Problem Behavior:**

Please indicate the *number of instances* and the *type* of problem behavior (tolerated or intolerated, as described below) displayed in the routine **today** (E.g., 1,2, or 3 tolerated; 1 intolerated; none): \_\_\_\_\_

**10. Overall Level of Problem Behavior Severity:**

When problem behavior is displayed by your child in the problematic routine, please rate the overall level of severity of the behavior(s):

None	Mild	Moderate	Severe
0	1	2	3
			4
			5

**11. Notes:** Please note any co-occurring illnesses/allergies/conditions (such as menses, an injury, etc.) that may be present **today**. Also please indicate if you administered over-the-counter medications (e.g., Advil, Tylenol) or any other medications that your doctor may have prescribed (e.g., antibiotics). \_\_\_\_\_

**Session termination criteria:**

- 1 instance of “intolerated” problem behavior
- 3 instances of “tolerated” problem behavior

**“Intolerated” problem behavior:**

- Aggression (e.g., hitting, kicking, biting others)
- Self-injurious behavior (e.g., hitting head, biting hand)
- High level of property destruction (e.g., rips up/destroys material, throws items)
- Tantrum behavior
- Dropping to floor/withdrawal/refusal to respond (lasting more than 5 mins)
- Elopement (leaves immediate area prior to task completion) lasting longer than 3 min
- More than 30 s of screaming

**“Tolerated” problem behavior:**

- Brief episodes of screaming, verbal protests (less than 30 s)
- Stomping feet on floor
- Low level property destruction (e.g., crumbles paper, pushes material aside)
- Dropping to floor/refusal to respond (lasting less than 5 mins)
- Elopement (leaves area prior to task completion), returns to task within 3 mins

## Appendix G

### Direct Observation Rating Form

**Participant:** \_\_\_\_\_ **Observer:** \_\_\_\_\_

**Activity/Routine:** \_\_\_\_\_

**Side Effect(s):** \_\_\_\_\_

**Problem behavior(s):** \_\_\_\_\_

To be used during observations in the experimental contexts by primary investigator and second researcher. Please provide the following ratings during the observation of the child in the specified routine. A description of terms is provided below.

**1. Start time of routine:** \_\_\_\_\_ **End time:** \_\_\_\_\_

**2. Latency to session termination:** \_\_\_\_\_

(The amount of time that elapsed before the session was terminated due to problem behavior or successful completion of the activity).

**3. Number of steps in routine completed:** \_\_\_\_\_

**4. Reason for session termination:** \_\_\_\_\_

(1 instance of untolerated problem behavior; 3 instances of tolerated problem behavior; or successful completion of activity)

**5. Problem Behavior:**

Please indicate the number of instances and the type of problem behavior (tolerated or untolerated, as described below) displayed in the routine **today** (E.g., 1,2, or 3 tolerated; 1 untolerated; none): \_\_\_\_\_

**6. Notes:** Please note any co-occurring illnesses/allergies/conditions (such as menses, an injury, etc.) that may be present **today**. Also please indicate if you administered over-the-counter medications (e.g., Advil, Tylenol) or any other medications that your doctor may have prescribed (e.g., antibiotics). \_\_\_\_\_

**Session termination criteria:**

- **1** instance of “untolerated” problem behavior
- **3** instances of “tolerated” problem behavior

**“Untolerated” problem behavior:**

- Aggression (e.g., hitting, kicking, biting others)
- Self-injurious behavior (e.g., hitting head, biting hand)
- High level of property destruction (e.g., rips up/destroys material, throws items)
- Tantrum behavior
- Dropping to floor/withdrawal/refusal to respond (lasting more than 5 mins)
- Elopement (leaves area prior to task completion) lasting longer than 3 mins
- More than 30 s of screaming

**“Tolerated” problem behavior:**

- Brief episodes of screaming, verbal protests (less than 30 s)
- Stomping feet on floor
- Low level property destruction (e.g., crumbles paper, pushes material aside)
- Dropping to floor/refusal to respond (lasting less than 5 mins)
- Elopement (leaves area prior to task completion), returns to task within 3 mins

## Appendix H

### **Treatment Acceptability Questionnaire**

(adapted from Albin, et al., 1996)

1. Do the intervention strategies address your highest priority goals for your child and family?
2. Are you comfortable with what you are expected to do during the intervention?
3. Are you comfortable with what others are expected to do during the intervention?
4. Do the intervention strategies recognize and support the needs of your family?
5. Overall, how well do the intervention strategies fit with your values and beliefs about raising a child with a disability and creating a meaningful family life together?
6. Do the intervention strategies recognize and build on your family's strengths?
7. All things considered, how difficult will it be for you to implement the intervention strategies?
8. Do you believe the intervention strategies will be effective?
9. If the intervention strategies are effective, do you believe that you can implement the techniques over a long period of time?

## Appendix I

### Intervention Fidelity Checklist for Experimental Contexts Associated with Each Study

#### STUDY 1

Date:	Alexa	Date:	Scott	Date:	Robby
<b>Intervention Strategy</b>		<b>Intervention Strategy</b>		<b>Intervention Strategy</b>	
Visual schedule		Visual schedule		Visual schedule	
Advanced verbal warnings		Task modification		Modifying the routine	
Embedding		Interspersing tasks		Behavior momentum	
Functional Communication Training		Advanced verbal warnings		Choice making opportunities	
Relaxation Strategies		Functional Communication Training		Functional Communication Training	
		Relaxation Strategies		Relaxation Skills	

#### STUDY 2

Date:	Jack	Date:	Ellie	Date:	Neil
<b>Intervention Strategy</b>		<b>Intervention Strategy</b>		<b>Intervention Strategy</b>	
Visual schedule		Visual schedule		Social Story	
Visual representation of time		Modifying the routine		Visual representation of time	
Advanced verbal warnings		Neutralizing routine		Neutralizing routine	
Embedding		Provide access to snack		Choice of activity reinforcer	
Functional Communication Training		Functional Communication Training		Relaxation Skills	
Choice making opportunities		Relaxation Strategies			

#### STUDY 3

Date:	Alana	Date:	Adam	Date:	Mark
<b>Intervention Strategy</b>		<b>Intervention Strategy</b>		<b>Intervention Strategy</b>	
Visual schedule		Visual schedule		Visual schedule	
Visual representation of time		Visual representation of time		Choice of activity reinforcer	
Advanced verbal warnings		Advanced verbal warnings		Video Self-Modeling	
Transition item		Provide access to reinforcer		Neutralizing routine	
Choice making opportunities		Functional Communication Training		Relaxation Skills	
Self-regulation skills		Relaxation Strategies			
		Choice making opportunities			



Table 1

*Participant Characteristics*

Participant	Age	Diagnosis	Full Scale IQ (M=100, SD=15)*	Medication Regimen	Experimental Context
Alexa	15	Pervasive Developmental Disorder, NOS	Stanford Binet: 73	Oxcarbazepine, Methylphenidate, Clonidine	Mealtime Routine
Scott	8	Asperger's Disorder	WISC-IV: 110	Aripiprazole, Amphetamine salts	Homework Routine
Robby	14	Autistic Disorder	Stanford Binet: 40	Risperidone, Benzotropine, Valproic acid	Household Chores Routine
Jack	12	Autistic Disorder	Leiter-R: 60	Risperidone, Clomipramine, Lorazepam	Eating in Restaurants
Ellie	11	Autistic Disorder	Stanford Binet: 42	Risperidone, Valproic acid	Grocery Store Routine
Neil	14	Autistic Disorder	Stanford Binet: 42	Quetiapine fumarate, Paroxetine, Topiramate, Lorazepam	Weekly Medical Appointment
Alana	9	Pervasive Developmental Disorder, NOS	WISC-IV: 53	Carbamazepine, Paroxetine, Clonazepam	Transitioning to/from Car
Adam	13	Autistic Disorder	Stanford Binet: 67	Aripiprazole, Topiramate, Catapres, Trazadone, Lorazepam	Morning Transition to School
Mark	19	Autistic Disorder	Leiter-R: 65	Oxcarbazepine, Risperidone, Fluoxetine	Transitioning during Community Outings

\*Stanford Binet-5 = Stanford-Binet Intelligence Scale: Fifth Edition

WISC-IV = Wechsler Intelligence Scale for Children: Fourth Edition

Leiter-R = Leiter International Performance Scale-Revised

Table 2

*Mean Ratings in Baseline and Post-intervention and Significance Levels for Assessment Measures of Problem Behavior and Quality of Life*

Measure	Baseline	Post- Intervention	Significance Level
Structured Interview for Assessment of Medication Side Effects			
Level of Side Effect Intensity Rating (1-5)	4.56	4.22	$p = 0.20$
Level of Difficulty Rating (1-5)	4.67	1.56	$p < 0.05$
Level of Problem Behavior Severity Rating (1-5)	4.44	1.67	$p < 0.05$
Aberrant Behavior Checklist-Community			
Irritability Subscale	19.33	15.44	$p < 0.05$
Home Situations Questionnaire			
Number of Problematic Routines	11.44	9.22	$p < 0.05$
Severity of Problem Behavior	5.78	4.83	$p < 0.05$
Resident Lifestyle Inventory	10.22	12.89	$p < 0.05$
Parenting Stress Index	108.00	103.11	$p < 0.05$
Developmental Disabilities Parent Depression/Stress Questionnaire	25.11	22.67	$p < 0.05$

Table 3

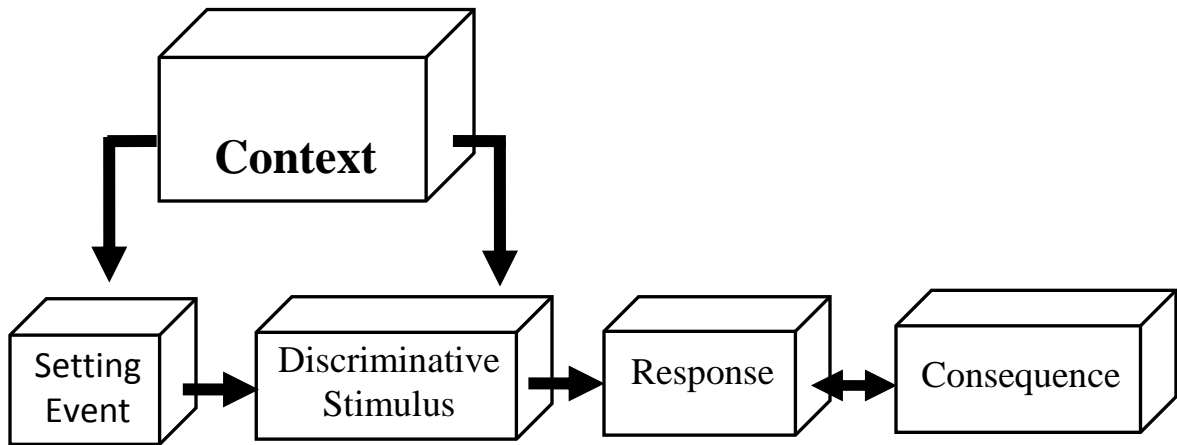
Mean Ratings for Post-intervention Measures of Global Improvement and Social Validity

Measure	Post-Intervention
Clinical Global Impressions (CGI)*	
Global Improvement Subscale	1.66
Global Social Validity Index (GSVI)**	
Ease of Use	4.3
Ability to Generalize	4.0
Overall Effectiveness	4.7

\**Note:* Global Improvement was rated on a 7-point scale, with 7 representing “very much worse,” 4 representing “no change,” and 1 representing “very much improved.”

\*\**Note:* Each of the three items on the GSVI was rated on a 5-point scale, with higher scores indicating greater ease utilizing intervention strategies, greater ease generalizing techniques to different contexts, and a greater overall level of effectiveness in reducing problem behavior.

Figure 1. A conceptual model for understanding problem behavior.



<b>A.</b> No Fatigue	“Take a shower”	Child complies	Parent praises
<b>B.</b> Fatigue (Due to lack of sleep)	“Take a shower”	Aggressive behavior	Escapes/avoids
<b>C.</b> Drug-induced Fatigue (Due to side effect)	“Take a shower”	Aggressive behavior	Escapes/avoids

Figure 2. Percentage of routine steps completed for three participants in the baseline and intervention phases of Study 1 (Context: Home-based Routines).

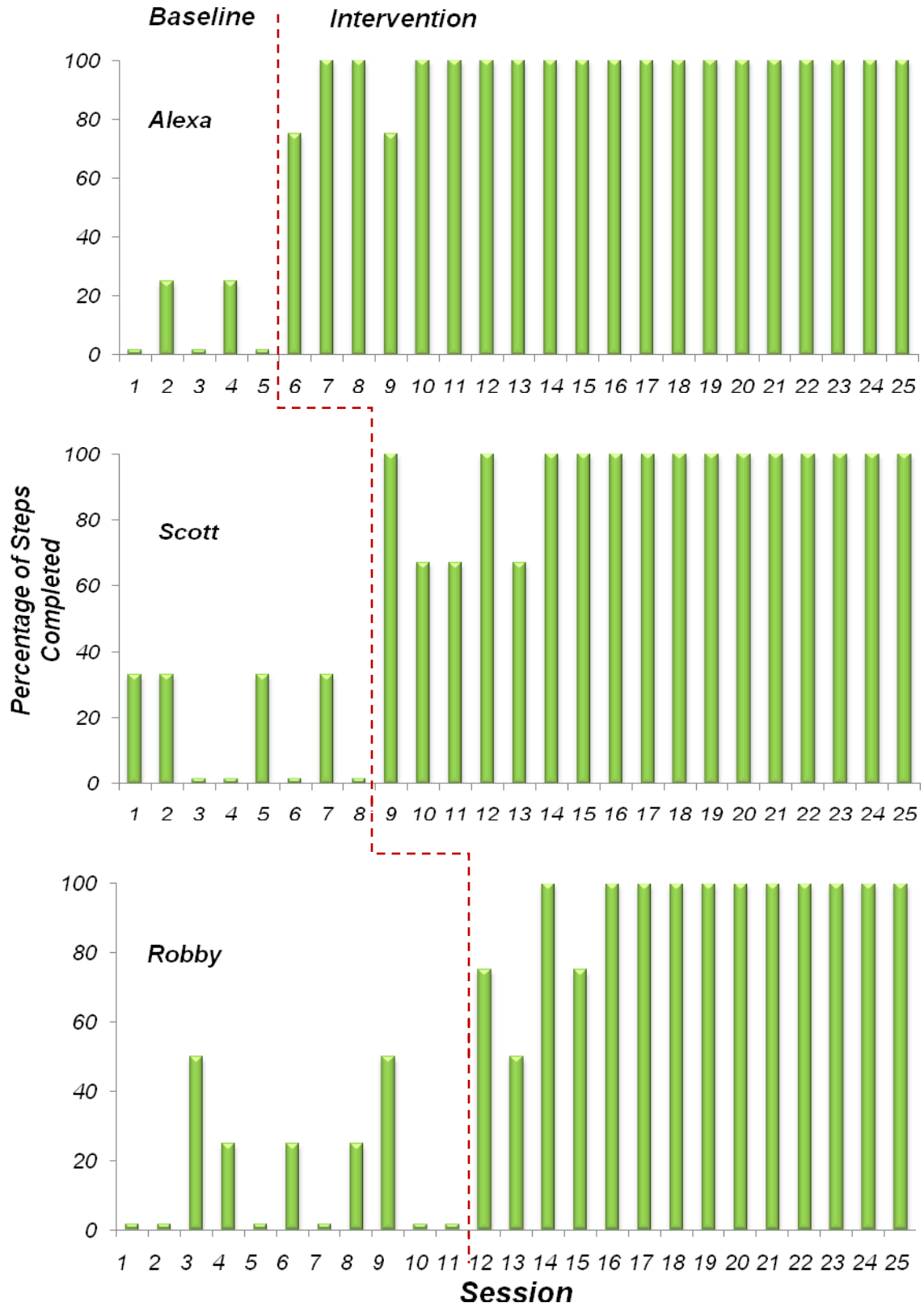


Figure 3. Latency to session termination for three participants in the baseline and intervention phases of Study 1 (Context: Home-based Routines).

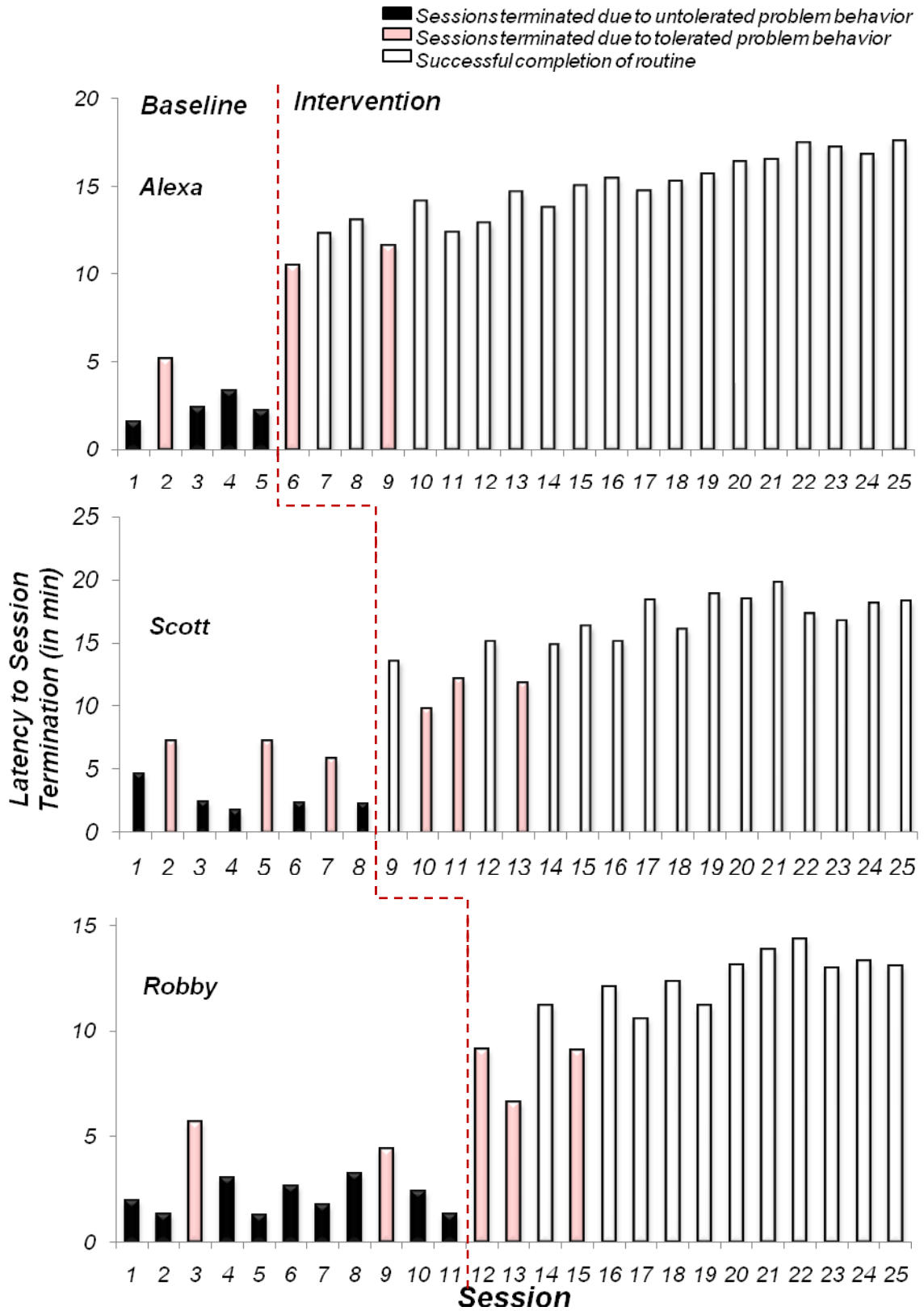


Figure 4. Ratings of the level of intensity of medication side effects present in the experimental context, the level of difficulty of the routine, and the level of severity of problem behavior displayed in experimental context, as rated on 5-point Likert scales ranging from 1 “mild” to 5 “severe,” for three participants in the baseline and intervention phases of Study 1 (Context: Home-based Routines).

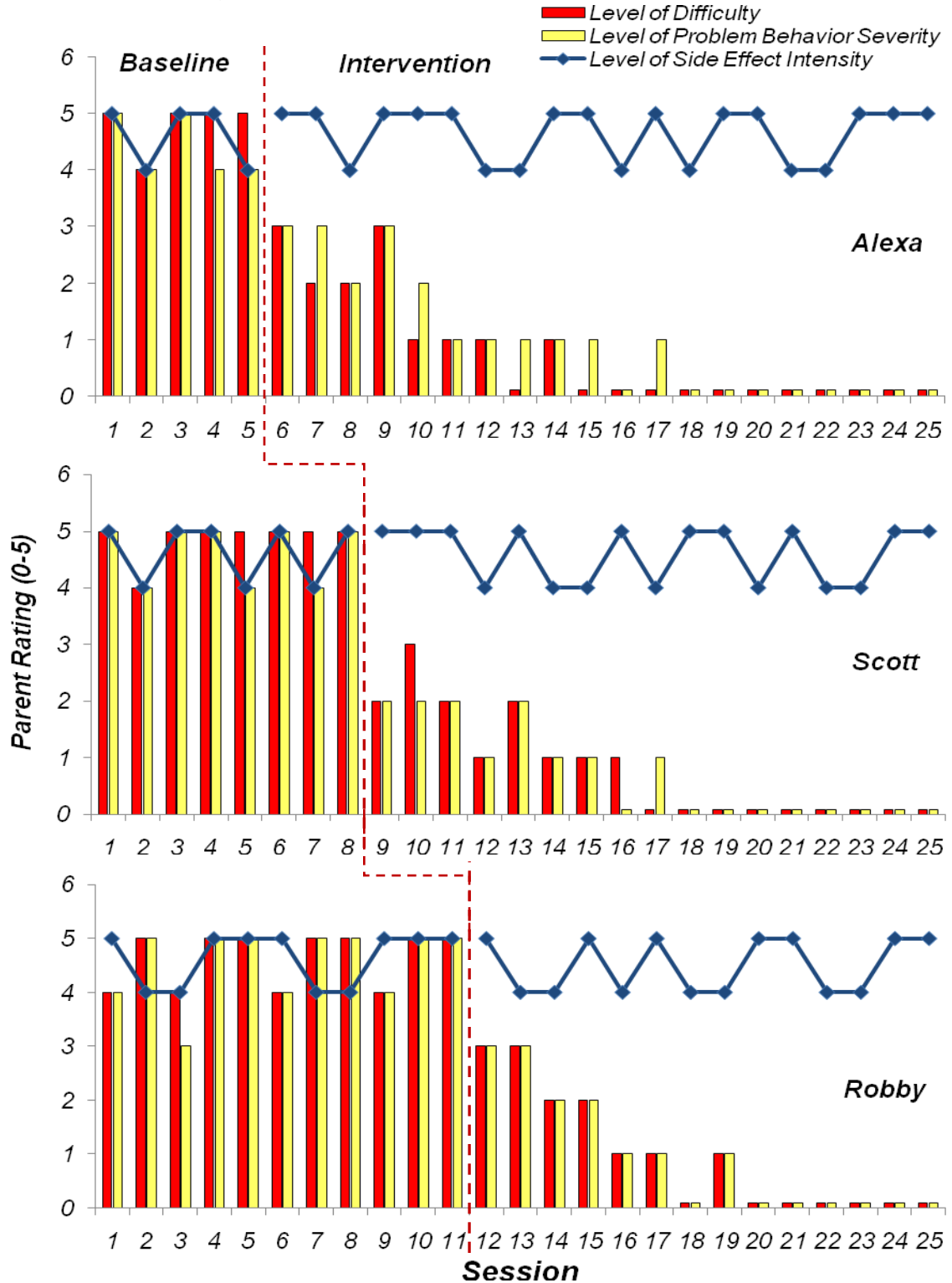


Figure 5. Percentage of routine steps completed for three participants in the baseline and intervention phases of Study 2. (Context: Community-based Routines).

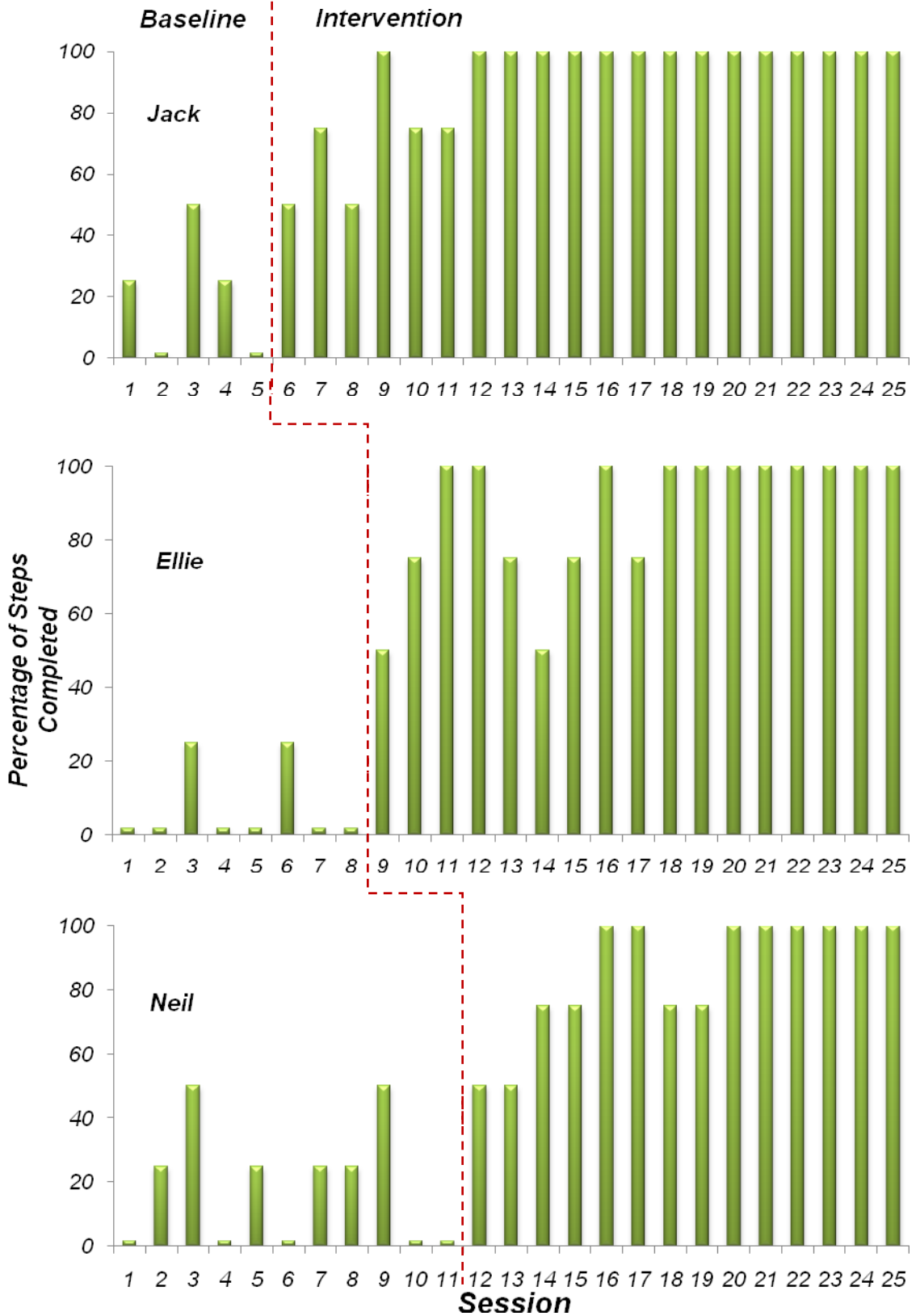




Figure 6. Latency to session termination for three participants in baseline and intervention phases of Study 2 (Context: Community-based Routines).

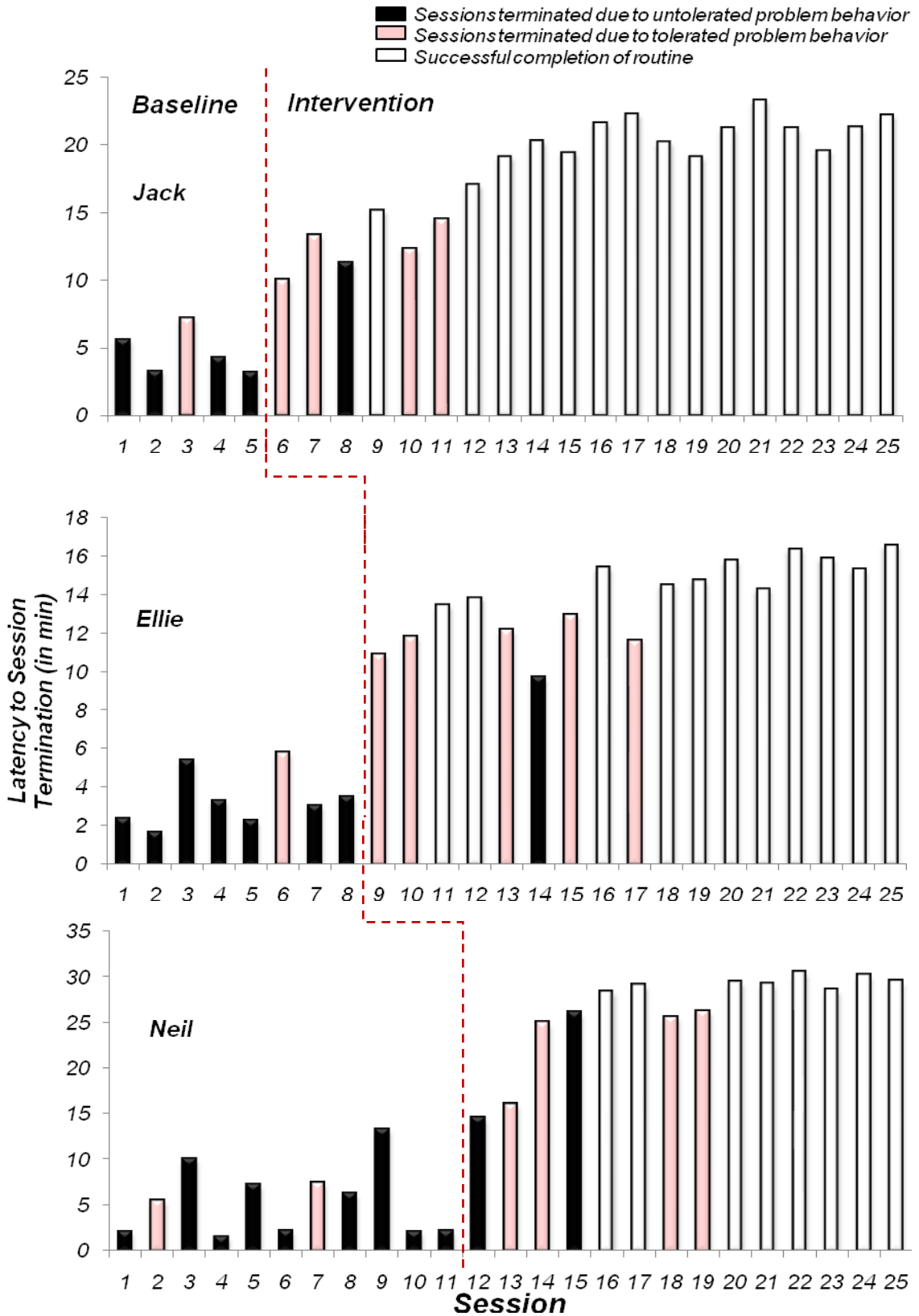


Figure 7. Ratings of the level of intensity of medication side effects present in the experimental context, the level of difficulty of the routine, and the level of severity of problem behavior displayed in experimental context, as rated on 5-point Likert scales ranging from 1 “mild” to 5 “severe,” for three participants in the baseline and intervention phases of Study 2. (Context: Community-based Routines).

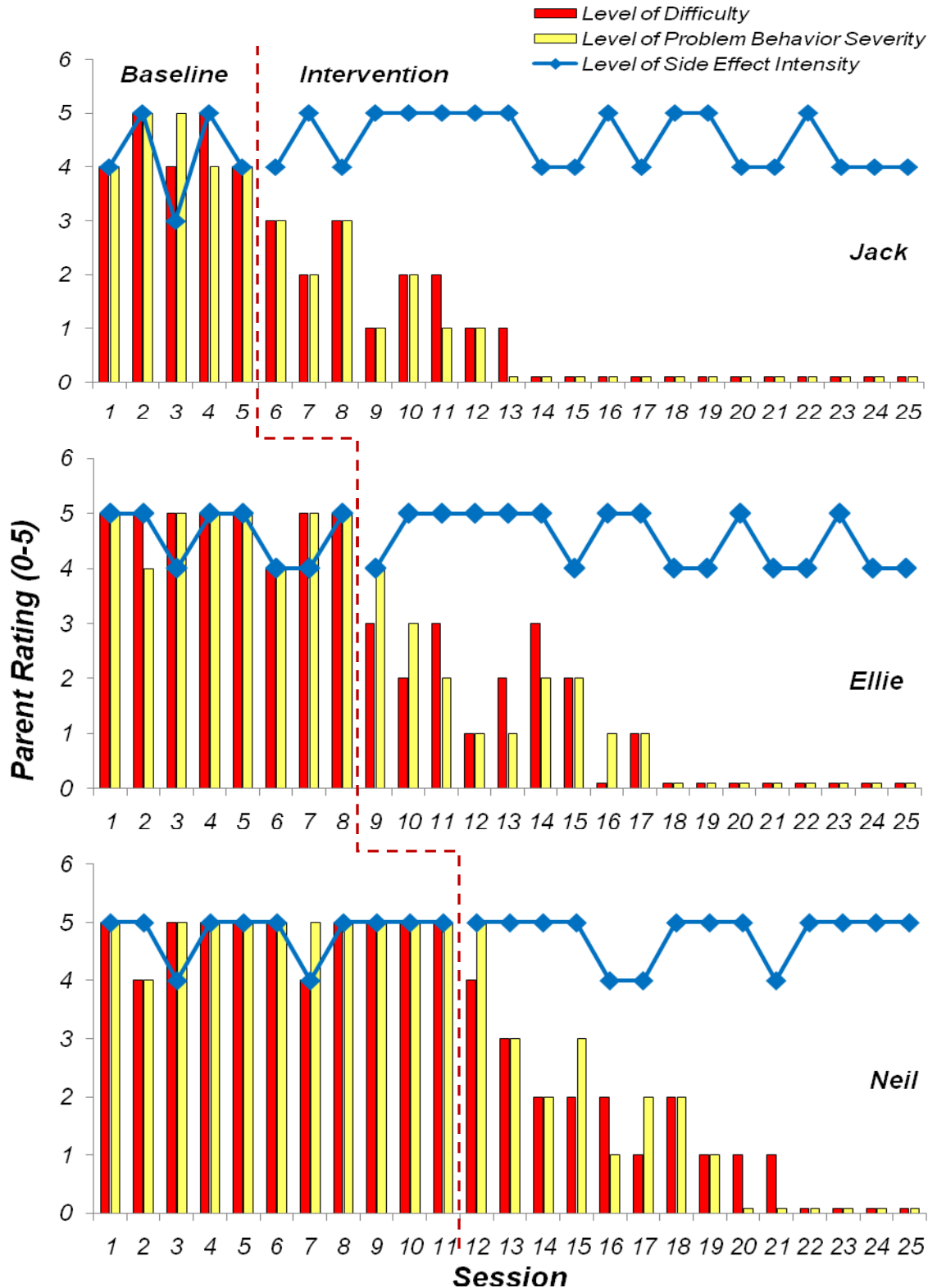


Figure 8. Percentage of routine steps completed for three participants in the baseline and intervention phases of Study 3 (Context: Transition-based Routines).

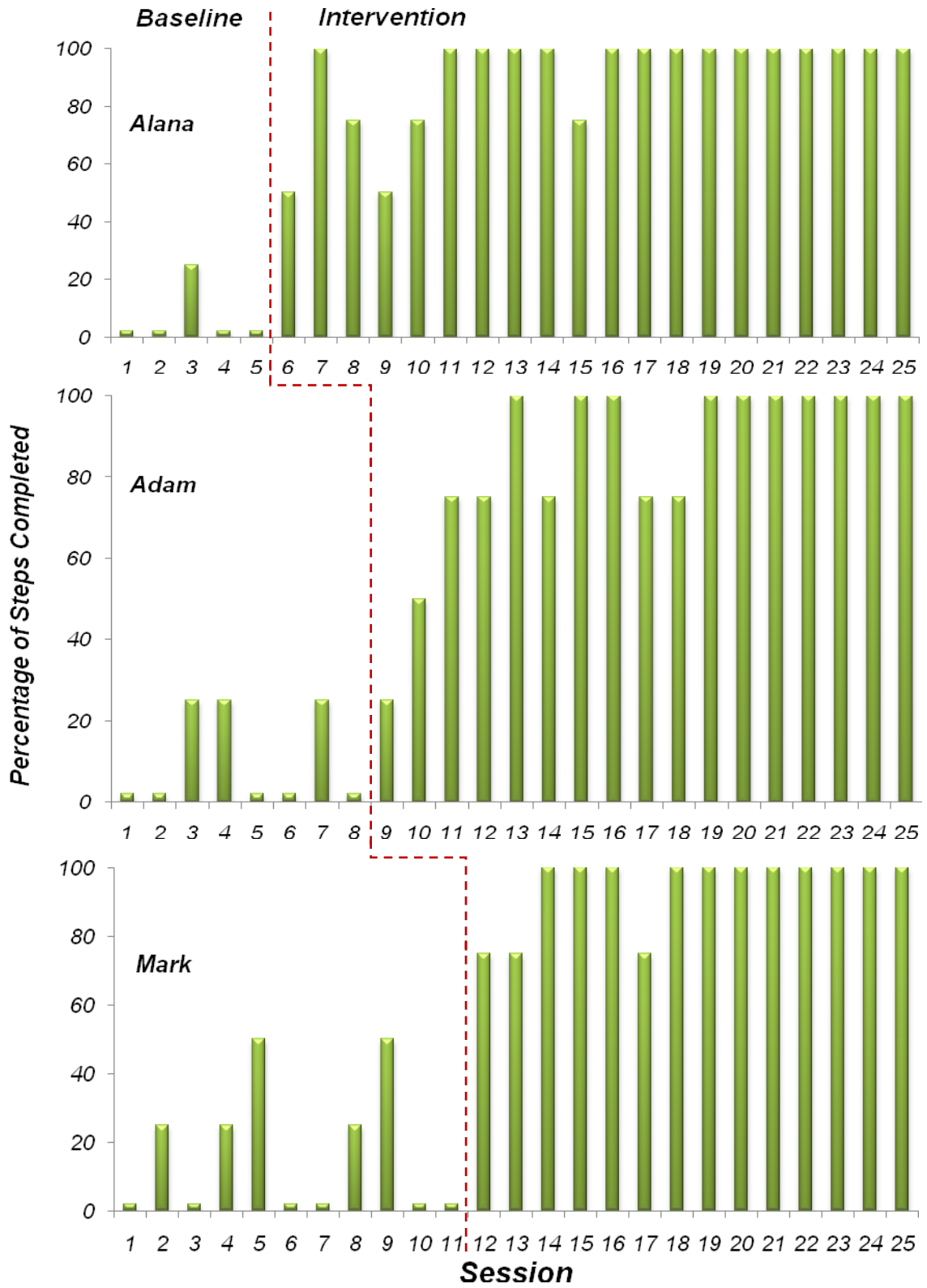


Figure 9. Latency to session termination for three participants in the baseline and intervention phases of Study 3 (Context: Transition-based Routines).

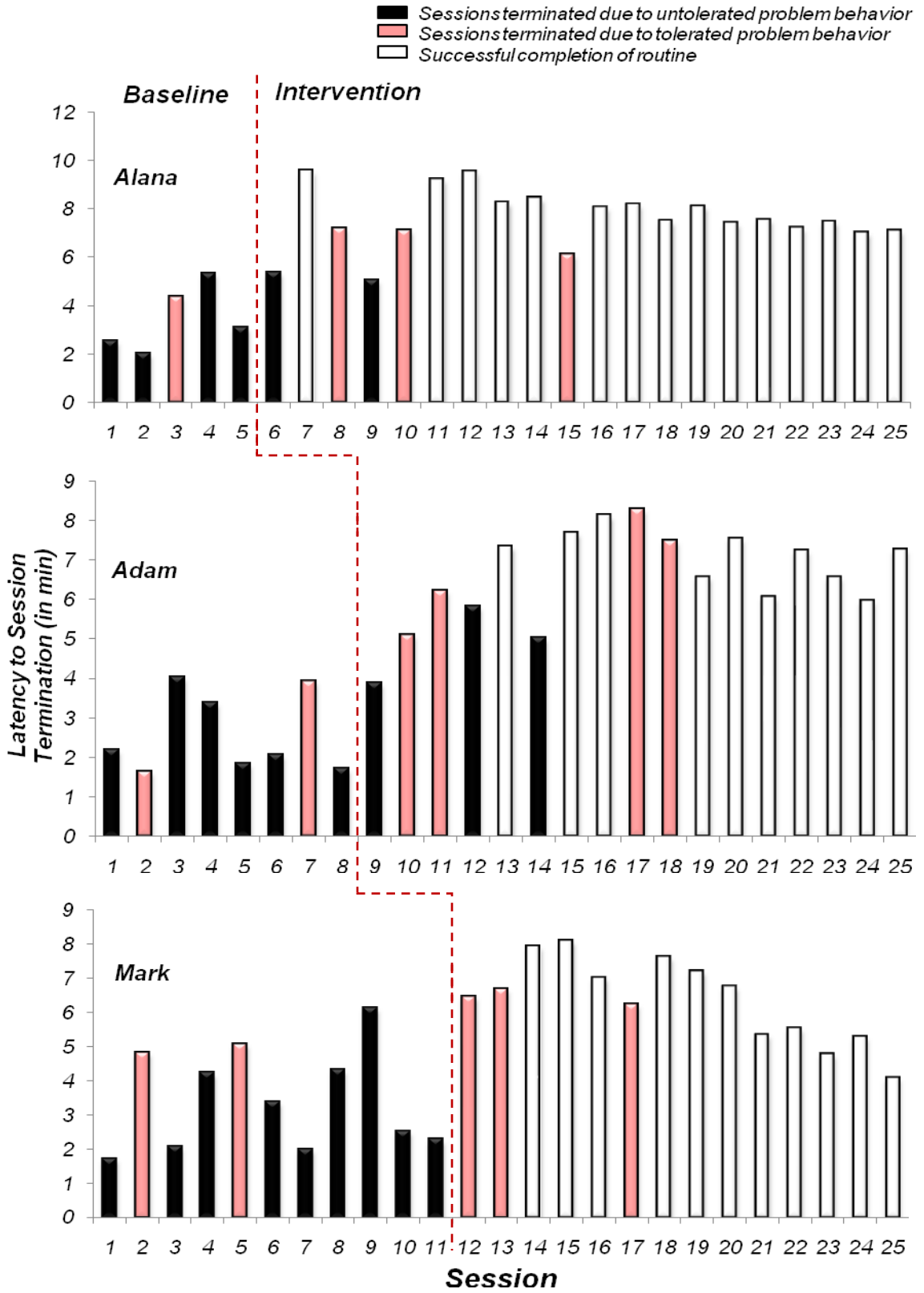


Figure 10. Ratings of the level of intensity of medication side effects present in the experimental context, the level of difficulty of the routine, and the level of severity of problem behavior displayed in experimental context, as rated on 5-point Likert scales ranging from 1 “mild” to 5 “severe,” for three participants in the baseline and intervention phases of Study 3 (Context: Transition-based Routines).

