Predictors of Adherence to Treatment by Parents in a Behavioral Intervention
Curriculum for Children with Autism Spectrum Disorders

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Dedication

This dissertation is dedicated to all of the families, young people, colleagues, and mentors I have been lucky to work with along my professional and academic journey, whose unquantifiable lessons do not appear on any transcript.
Abstract

Information on the extent to which parents of children with intellectual and developmental disabilities adhere to prescribed behavioral treatments is limited. In this treatment adherence study, parents (n=21) of children with autism spectrum disorders were surveyed regarding implementation of intervention strategies for skills instruction and problem behavior management. All parents had participated in a standardized parent training curriculum through a community service provider specializing in treatment based in applied behavior analysis for children with autism spectrum disorders and their families. Four variables were significantly correlated with reported adherence, three of which (agreement with spouse on implementation of interventions, perceived effectiveness as a behavior change agent, confidence in the intervention to produce meaningful change) were theoretically related and highly correlated (α=.71) and included in a linear regression as a single factor (labeled ‘assurance’) along with the variable of perceived acceptance of the child in family and community activities. The full model explained 53% of the variance in reported adherence (p<.001), and the ‘assurance’ contributed a significant amount of unique information to the model (p<.002). The implications of parent perception in explanatory frameworks for adherence are discussed and next steps in research are suggested.

Key Words: adherence; parent skills training; applied behavior analysis; autism
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Chapter I

Adherence Defined

Adherence to prescribed therapeutic or prophylactic regimens involves an individual carrying out a set of behaviors consistent with the recommendations of, and in the absence of oversight by, the prescribing physician or clinician (Meichenbaum & Turk, 1987; Sackett & Haynes, 1976). Sub-optimal adherence to prescribed treatment has been a well-documented problem in the medical and behavioral health literature for the past 60 years (e.g., Meichenbaum & Turk, Nock & Ferriter, 2005). When treatment regimens are not adhered to as prescribed, by individuals themselves or their caregivers, best outcomes cannot be achieved and proper evaluations of treatment effectiveness cannot be made. This holds for therapeutic regimens in the course of treating biological or neurological disease, psychological or psychiatric disorder, prophylactic regimens, and clinical trials evaluating efficacy or effectiveness of an otherwise promising treatment. For an individual to be considered adherent to a recommended treatment, a wide variety of behaviors may be required such as keeping appointments, consuming medication according to schedule, making lifestyle changes (e.g., diet and exercise), performing home-based therapeutic regimens, and avoiding behavior inconsistent with healthy goals or other intended treatment outcomes (Meichenbaum & Turk, Sackett & Haynes).

The economic impact in the United States of non-adherence to recommended treatments by physicians is estimated as high as $300 billion annually (DiMatteo, 2004). Liptak (2006) reports average medical costs for children with autism exceed $6000
annually, approach $6000 for children with depression and $1600 for those with intellectual disability, while average costs for other children are less than $900 per year. The estimates reported by DiMatteo and Liptak do not account for the cost of non-adherence to treatments recommended by psychologists, psychiatrists, or special education and habilitative services such as early childhood education/early intervention, occupational therapy, speech therapy, or physical therapy, all of which are frequent components of care regimens for children with developmental disabilities. Estimates generated in Great Britain (Jarbrink & Knapp, 2001) and in the United States (Jacobson, Mulick, & Green, 1998) suggest $4.0 million spent on educational and habilitative services for each individual with autism over the life course. It is unclear to what extent non-adherence impacts these costs, but non-adherence to effective treatment recommendations results in the cost of re-implementation of interventions and perhaps abandonment of otherwise effective interventions in favor of less-suitable strategies.

The problem of non-adherence is recognized not only at the level of research and practice but also in the context of clinical drug trials. The United States Food and Drug Administration (FDA, 1997) in their Good Guidance for Practice document outlining the standards for drug trials mandated that compliance measures be part of the evaluation process and criteria established for exclusion from trials based on non-adherence. The World Health Organization has recognized the detrimental effects of non-adherence and has called for international action to counteract non-adherence to medical treatment recommendations, which averages nearly 50% in developed countries (Sabate, 2003).
The prevalence of non-adherence to physician recommendations overall is estimated at 24% (DiMatteo, 2004). Others have estimated non-adherence in a variety of disease conditions for a variety of regimens. For example Lemanek, Kamps, and Chung (2001), in a review of research in juvenile rheumatoid arthritis, type 1 diabetes, and asthma found between 30-98% non-adherence to drug and related therapies. Meichenbaum and Turk (1987) reported that prophylactic medical regimens were adhered to with only 30-35% accuracy. Osterberg and Blaschke (2005) reported only 50-70% of psychiatric patients adhered to medication regimens. Gould, Shaffer, and Kaplan (1985) suggest that 40-60% of mental health treatment recipients terminate services prior to clinician recommendations. Pediatric psychopharmacology research has a limited body of research on medication adherence by parents. In a review of 35 years of research Hack and Chow (2001) found only seven peer-reviewed experiments on adherence in pediatric psychopharmacology, all of which evaluated parent adherence to treatment regimens for attention deficit hyperactivity disorder. Reported adherence rates were 56-75%.

Parent non-adherence is widespread across a variety of behavioral health treatment regimens, including 37% non-adherence to behavior change recommendations following outpatient therapy for child defiance and disruption (MacNaughton and Rodrigue, 2001), 40% premature termination from child and parent therapy to remediate oppositional behavior and conduct disorder (Kazdin, Holland, & Crowley, 1997), and 70% incidence of family resistance displayed during skills training
for management of child problem behavior (Chamberlain, Patterson, Reid, Kavanagh, & Forgatch, 1984; Patterson & Chamberlain, 1994).

Interventions for children with intellectual and developmental disabilities (IDD) are frequently grounded in the principles of applied behavior analysis (ABA), particularly for children with autism spectrum disorders, and routinely include parent skills training as an adjunct to clinical treatment, if not the primary treatment delivery route (e.g., Arkoosh et al., 2007; Cowart, Iwata, & Poynter, 1984; Feldman, Case, Rincover, Towns, & Betel, 1989; Feldman, Case, Garrick, MacIntyre-Grande, Carnwell, & Sparks, 1992; Green, Brennan, & Fine, 2002; Huynen, Lutzker, Bigelow, Touchette, & Campbell, 1996; Kashinath et al., 2006; Love & Van Biervliet, 1984; Lowry & Whitman, 1989; Small, 2007; Tymchuk & Andron, 1988). The extent to which the treatment regimen is adhered to following training in the absence of clinical oversight is a critically important determinant of whether that treatment will produce meaningful and lasting results. Treatment follow-through is generally indexed by observational measures of treatment integrity (Gresham, 1993). Treatment integrity has been defined as the degree to which an independent variable is presented as defined (Peterson, Homer, & Wonderlich, 1982), or a treatment is implemented as designed (Gresham, Gansle, & Noell, 1993). Also referred to as treatment fidelity, intervention fidelity, and treatment strength, treatment integrity has received attention recently in behavior analysis and educational research as much for its under-reporting as well as its necessity in practice (Arkoosh et al., 2007; Brown-Chidsey, 2005; Gresham et al., 1993).
Measuring and reporting treatment integrity is central to any analysis of the relationship between independent and dependent variables. Demonstrating the integrity of independent variable implementation supports a claim of functional control over a dependent variable, and by extension to the appropriateness of recommending continuation or discontinuation of a treatment regimen. In consultative contexts such as classrooms and family homes where child skill acquisition and problem behavior reduction are often the intended clinical outcomes, teachers and parents are generally told they must continue to perform the skills they’ve learned when clinical supports are withdrawn to maintain behavioral changes realized when clinical supports were in place.

Observational data demonstrating generalization of treatment integrity across contexts, people, or materials, and maintenance of intervention skills and clinical outcomes across time is current best-practice for researchers in efficacy trials of behavior change interventions. These data are also the foundation for claims of the likelihood of success post-training in the absence of clinical oversight under naturally-occurring conditions. Studies involving skills training and other behavior change techniques for parents of children with intellectual and developmental disabilities suggest that parents can implement strategies with acceptable integrity and can generalize these skills across time and contexts when directly observed doing so (e.g., Cowart, et al., 1984; Feldman, et al., 1989; Feldman, et al., 1992; Huynen, et al., 1996; Love & Van Biervliet, 1984; Lowry & Whitman, 1989; Tymchuk & Andron, 1988).
A limitation of treatment integrity measures is that performance observed by research staff occurs under conditions that may be more optimal than those occurring in natural contexts. Parents are generally aware well in advance of any scheduled observation, preparations are made to leave sufficient time in the family schedule for the experimenter’s visit to the home, and when observed parents are apt to behave in accordance with the expectations of the observer (i.e., reactivity - for a detailed discussion refer to Nelson & Hayes, 1981). When interventions are implemented in situ, without clinical support or research staff, integrity may deteriorate resulting in mis-application and reduced effectiveness. This is the problem of treatment adherence and it remains unaddressed in behavior analysis and educational research (Allen & Warzak, 2000). Several authors have called for measurement of behavior between treatment integrity observations, as well as post-training, to generate more robust indicators of parent performance in the absence of clinical oversight (Allen & Warzak, 2000; Breiner, 1989; Charman & Howlin, 2003; Springer & Reddy, 2004). Others have begun to bridge the research gap between treatment integrity and treatment adherence by investigating the level of integrity required to achieve or maintain clinically meaningful outcomes at home (Arkoosh et al., 2007) in inpatient settings (Northup, Fisher, Kahng, Harrel, & Kurtz, 1997), and at school (Sterling-Turner, Watson, & Moore, 2002; Vollmer, Roane, Ringdahl, & Marcus, 1999; Wilder, Atwell, & Wine, 2006), finding that level of integrity is indeed related to observed clinical outcome, and that under some circumstances child behavior may be robust to deterioration in treatment integrity.
Although children with IDD/ASD are routinely the subjects of research and clinical services in ABA, and their parents, as end-users of interventions regularly participate in research involving treatment integrity, adherence per se remains a relative unknown in this population.

Adherence research in medicine and behavioral health reveals a limited consensus on the relative impact of predictors of non-adherence (non-adherence has been a concern in medicine for several decades – see DiMatteo, 2004; Meichenbaum & Turk, 1987). Blackwell (1976) observed that adherence is determined by a unique interaction between patient, illness, clinician, treatment, and environment. This remains, broadly, an accurate summary of the extant literature and calls clinical researchers to investigate the importance of variables that may impact adherence among their unique clientele, in the environmental circumstances relevant to them, given the requirements of the recommended treatment. Recently, behavioral health and IDD investigators have identified parent perception of a variety of personal and environmental characteristics as predictive of participation in treatment for their children. Studies in the context of outpatient therapy with children who exhibit aggressive and oppositional behavior, and their parents (e.g., Kazdin et al., 1997, Kazdin & Wassel, 1999), suggest that the total amount of barriers a parent perceives to be interfering with their participation is predictive of early termination. Further analysis suggested that perception of a lower amount of barriers acted as a protective factor for families at high risk for early termination. Perceived barriers included personal and family stressors, practical obstacles in travelling to treatment sessions, irrelevance of the treatment, and poor
relationship with the therapist. The effect of perceived barriers in regression models was not explained by parent, family, or child characteristics (i.e., perceived barriers added unique information to the models). The implications for intervention are clear: relatively static characteristics that routinely contribute to early termination from treatment (e.g., socio-economic status, parent mental health, child history of anti-social behavior) are difficult or impossible for a parent skills trainer or child therapist to impact, whereas barriers to treatment may prove malleable and when reduced or removed could result in higher likelihood of participation in treatment, persistence in treatment, treatment completion, and clinically-meaningful outcomes.

Parent perception of the context in which their family lives, their impact as behavior change agents, and the broader outcomes they are able to generate for their children have been associated with the likelihood of parent engagement in treatment for their children in IDD research. In a survey of 48 parents participating in an early intensive behavioral intervention (EIBI) with their children with autism, Solish and Perry (2008) reported self-efficacy, knowledge about the intervention, and belief in the intervention to be significant predictors of parent involvement. Self-efficacy alone accounted for 50% of the variance, after accounting for child characteristics. Indeed, these and other factors may be critical in parents remaining involved as interventions become increasingly entwined with parenting and the impacts on child behavior are slow and incremental. Grindle, Kovshoff, Hastings, and Remington (2008) conducted a qualitative study with parents responsible for delivering or managing home-based EIBI programs for their children with autism and had persisted in programming for at least
two years. Mothers and fathers reported increased support at home via the EIBI program and improvements in child communication and socialization, though a minority reported deterioration of the marital relationship. Subjective reports of perception of barriers and experiences are not common for behavioral researchers to consider in empirically-based selection of independent variables for manipulation or evaluation. However as these and other researchers continue to suggest (e.g., Ajcek, 1991; Spoth and Redmond, 1995), perceived benefits of and barriers to participation, as well as perceived capacity to effect change, will impact parents’ decisions to participate and persist in programming that requires time, effort, and energy to generate best outcomes (as is almost always the case in behaviorally-based intervention paradigms for individuals with IDD).

From a behavioral perspective, the parent behaviors of engagement, persistence, and adherence may be made more likely if the value of the behaviors is enhanced by removing barriers to participation and key reinforcers for the behaviors are present such as improved efficacy and child performance, and acceptability and inclusion in family and community. Given sustained verbal behavior by successful families relative to engagement, persistence, and adherence these behaviors may ultimately become more rule-governed across time as new families are faced with the decision to begin programming and take an active role. (Remington, 2010).

*Purpose of Current Study and Key Research Questions*

The purpose of this investigation is to extend the initial work of Moore and Symons (2009) on treatment adherence by parents of children with autism spectrum
disorders. Theirs was the first study to date examining the extent to which parents of children with ASD adhere to prescribed behavioral or medical interventions. In a single time-point survey study, parents (n=220) reported significantly greater adherence to medical treatment recommendations than behavioral treatment recommendations, and greater adherence to reinforcement-based recommendations (81.7%) than punishment-based recommendations (68.9%). One significant predictor of adherence to behavioral treatment was identified, namely that parents of children with Asperger’s syndrome reported lower adherence to behavioral treatment recommendations than parents who described their children as autistic. Although their study found differential adherence by type of behavioral treatment recommendation, many unknowns remained including the specific nature of the treatment recommendations, the type of clinician making the recommendation and his or her specific degree or certification/licensure, the clinician’s level of training and experience, and the type of training provided (if any) during initial acquisition of skills related to the treatment recommendations. The survey developed by Moore and Symons asked a limited amount of questions specific to family, parent, and child characteristics, and did not address potential reasons for non-adherence, limiting the utility of the results. The current study will be the first to address parent adherence in the context of a known intervention delivered by a single provider organization, and to explore the relationship of adherence to family, parent, and child characteristics, as well as social factors found in previous research to be associated with adherence and related engagement behavior of parents.
The following specific research questions were asked in the current investigation: 1) what family, parent, or child characteristics are associated with reported adherence by parents of children with ASD to behavior change skills they mastered during in-home training, 2) to what extent are parent perceptions of their own effectiveness, social supports, and acceptance of the child into community and family, as well as confidence in the intervention to produce meaningful outcomes, associated with reported adherence, and 3) to what extent is treatment integrity, as indexed by sessions-to-criterion, predictive of reported adherence?
Chapter II

Models of Adherence

Investigators in the medical and behavioral health fields have wrestled with the questions of what influences adherence and what can predict non-adherent behavior. A commonly-held belief is that adherence behavior is dynamic, and an evaluation of the pattern of adherence within the relationships between predictors and adherence outcomes is necessary to effectively inform adherence enhancement efforts (Farmer, 1999; Meichenbaum & Turk, 1987; Nock & Ferriter, 2005). In his assessment of adherence to medical regimens in psychiatry, Blackwell (1976) suggested that despite studying over 200 variables, no consistent results have emerged with respect to influence over adherence. He concluded that the extant knowledge suggests only that adherence is determined by a complex interaction between patient, illness, provider, treatment, and environment. Since Blackwell’s comments, researchers have struggled to produce more specific findings with any degree of generality or predictive utility, but recent research has suggested, broadly, that static characteristics of parent, child, and family, as well as perceived barriers and experiences, contribute substantially to adherence and related behaviors (Kazdin et al., 1997; Nock & Ferriter, 2005; Nock & Kazdin, 2001; Solish & Perry, 2008; Spoth & Redmond, 1995).

Several models of adherence have been proposed in an attempt to account for these and other potentially important predictors of adherence. Four specific models will be discussed below: the Health Belief Model, Barriers to Treatment Model, Instruction-Motivation-Behavioral Skills Model, and the Theory of Planned Behavior. Each offer
some direction within the complex interaction proposed by Blackwell and the supporting empirical research within each model suggests there are relationships between components of the models and adherence-related behaviors. Taken together, however, the evidence is limited and variable with respect to the explanatory sufficiency of any one of the models.

*Health Belief Model*

The health-belief model of care (HBM) has been described as a set of social-psychological variables that are useful in explaining and predicting the adherence behavior of individuals (Becker, Haefner, Kasl, Kirsch, Maiman, & Rosenstock, 1977; Becker & Maiman, 1975). They suggest a patient’s adherence to recommended treatment will depend on their standing along four dimensions: perceived susceptibility to illness, perceived severity of the illness, perceived benefits of adherence, and perceived costs of adherence. A patient’s standing on these dimensions interacts with demographic, social, and psychological variables, as well as environmental cues, to determine the likelihood of adhering to recommended health-related behaviors.

Research on the utility of the HBM consists of retrospective and prospective surveys compared against criterion health-related behavior. HBM research has not included parent adherence to regimens of care for their children as an outcome measure. Some of the earliest investigations within the HBM involved patients in prophylactic dental procedures and vaccinations (Kegeles, 1963; Rosenstock, Derryberry, & Carriger, 1959; Tash, O’Shea, & Cohen, 1967). In a prospective study on the likelihood of preventive dental visits, Kegeles (1963) found that perceived susceptibility was related to the
likelihood of future visits, while perceptions of severity and benefits were not related. These findings do not correspond with Tash et al. (1967) who found that individuals who believed they were not very susceptible to dental problems were likely to visit the dentist more regularly (a belief which could be a function of the frequent visits), as were those who believed dental problems to be serious but dental visits to be not costly or painful. In a meta-analysis of 16 studies evaluating the predictive utility of the HBM, Harrison, Mullen, and Green (1992) found 22 of 24 mean effect sizes to be positive and statistically significant. However, as the authors note those effect sizes indicate a strong relationship with one or another dimension of HBM, but do not reflect the explanatory or predictive utility of the entire model, nor the interactions between the model components. In fact, a maximum of 9% of the variance in health behavior was explained by any one of the HBM components. Harrison et al. also note the lack of homogeneity between the effect sizes, suggesting that either the measures are tapping different constructs or highlighting the real variation in the predictive utility of the model.

Survey and questionnaire items for HBM studies tend to be developed by the authors and have not undergone psychometric evaluation. For example, Brownlee-Duffeck, Peterson, Simonds, Goldstein, Kilo, and Hoette (1987) developed a questionnaire about health beliefs related to diabetes care. As is typical of studies investigating HBM, correlations were computed between questionnaire scores and an objective measure of health behavior (in this case, blood hemoglobin levels as an indicator of adherence to a prescribed insulin regimen). Significant correlations were
found between younger patient’s hemoglobin levels and their ratings of perceived susceptibility and severity of illness, as well as between older patient’s hemoglobin levels and perceived costs and benefits to adherence to the insulin regimen. Similarly Cummings, Becker, Kirsch, and Levin (1982) evaluated scores on an HBM questionnaire (developed by the authors) with blood levels and self-report on medication intake and dietary restrictions. Results suggested little relationship between answers to questions related to the HBM and adherence to medical and diet regimens. Cummings et al. provide an example of the relationship between the HBM and two other models of adherence reviewed here (Barriers to Treatment and Information-Motivation-Behavioral Skills, described below) by including several relevant items on their questionnaires. They found a significant relationship between adherence and various barriers to treatment such as being away from home, disruption to family life, and craving foods not allowed in a special diet. Additionally, the amount of information a patient had regarding treatment regimen was unrelated to adherence.

In related behavioral health research, McNaughton and Rodrigue (2001) found that belief about the form of service delivery may impact adherence to recommendations from a therapy screening appointment. Patients demonstrated 80% adherence to recommendations involving professionals outside the psychology field but only 40% adherence to recommendations for further psychological appointments. The authors categorized recommendations for behavior management programming as ‘active self-help’, to which 50% of parents adhered.
In summary, the strength of causal claims and generality of findings in HBM-related research is limited. Investigators typically make use of convenience samples in their immediate clinical environments, do not compare the utility of HBM against other models of adherence, rely on measurement tools with undefined psychometric properties, and rely on correlational analyses for claims about the relationships between scores on HBM measures and health-related behavior. Conclusions on the utility of the HBM are limited to single components of the model and exclude information on the overall predictive utility of the model or interaction effects between components. Harrison et al. (1992) suggest that the components of HBM may be valuable heuristics through which to approach the likelihood of patient adherence to treatment, but unless research emerges in support of the explanatory or predictive utility of HBM as a whole, discussion of the individual constructs as a collective model should cease.

**Barriers to Treatment Model**

Investigators in the behavioral health field have long been concerned with attendance at therapy sessions, attrition from and termination of therapy sessions, and resistance within parent training sessions in clinic. The barriers to treatment model proposes that the more barriers an individual perceives to experience, the less likely he or she is to engage in recommended behaviors such as attendance at therapy sessions or skills taught during training (Kazdin, et al., 1997), and to experience optimal effects from treatment regimens they do complete (Kazdin & Wassell, 1999). Perceived barriers include a variety of factors not necessarily related to parent, child, and family characteristics, such as complexity and demands of treatment, life stressors, relevance
of treatment, and support within the relationship with the treatment provider. Kazdin et al. (1997) found that the total amount of perceived barriers was significantly related to termination from therapy, an effect not explained by parent, child, or family characteristics.

Similar to research on the HBM, investigations within the barriers-to-treatment framework typically involve the study of one or more barriers and/or strategies to overcome a limited number of barriers (rather than all possible barriers an individual or family is experiencing at the study’s inception). This research usually takes place in a clinic context and has involved parent behavior extensively. Prinz and Miller (1994) found that taking time to talk with a parent about issues impacting their daily lives, unrelated to the therapeutic regimen for which they were responsible, resulted in fewer terminations from therapy. Sherbourne, Hays, Ordway, DiMatteo, and Kravitz (1992) also suggest that the quality of social supports for parents is more important than quantity with respect to adherence to prescribed protocols. For some parents, simply attending the first appointment or class is difficult. Dush and Stacy (1987) found that contact with parents prior to the first in a series of parent education classes resulted in an increased likelihood of attending that first class.

Once at the therapy appointment, therapists shoulder the burden of creating a therapeutic context in which learning is optimized and barriers to intended outcomes are reduced or eliminated. Patterson and Forgatch (1985) examined parent resistance in a behavioral skills training setting and found higher levels of resistance when therapists used statements designed to confront parent assumptions or teach them to perform new
skills, as compared to statements of support. Resistance has also been associated with early termination from therapy (Chamberlain, Patterson, Reid, Kavanagh, & Forgatch, 1984; Patterson & Chamberlain, 1994). Research on the barriers-to-treatment model as a whole is similar in structure to that in HBM investigations (Kazdin et al., 1997). Self-report questionnaires are the primary data gathering tool on the construct of interest (in this case, barriers to treatment), an objective criterion measure is identified, and correlations between the construct and that measure are calculated. External validity is questionable in this arrangement as barriers are studied within convenience samples coming into clinic settings. However strong experimental designs are evident in several investigations connected conceptually to the barriers-to-treatment framework. Prinz and Miller (1994) randomly assigned participants to two treatment groups in their study highlighting the impact of supportive conversations with parents unrelated to therapy issues. A causal claim has a stronger foundation in this study with respect to parents in the ‘extended’ treatment group terminating therapy less frequently. Similarly, Dush and Stacy (1987) randomly assigned participants to four treatment groups and demonstrated a causal relationship between pre-session contact and reduced levels of attrition. A third relevant example comes from Patterson and Forgatch (1985) who employed within-subject research design in their evaluation of the impact of therapist behavior on parent behavior in a clinic training setting. The A-B-A-B design used to evaluate parent non-compliance as a function of the type of therapist statements used during training
provided a repeated demonstration of the causal relationship between confrontational therapist statements and resistant parent behavior.

Information-Motivation-Behavioral Skills Model

The diverse body of adherence-enhancement strategies across research and clinical disciplines can be captured along three broad dimensions: educational, organizational, and behavioral (Lemanek et al., 2001). Conceptually, the Information-Motivation-Behavioral Skills (IMB) model proposed by Fisher, Fisher, Amico, and Harman (2006) suggests that all three are necessary for an individual to adhere to a prescribed regimen. The IMB model, developed as a prevention/adherence framework within HIV/AIDS research, holds that an individual must have the behavioral skills necessary for adherence, as well as sufficient information and motivation. Behavioral skills and environmental cues are said to mediate the effects of information and motivation in this model. The authors discuss ‘information’ in terms of its accuracy and completeness, ‘motivation’ in terms of social supports and the individual’s beliefs about the likely effects of the medication, and ‘behavioral skills’ in terms of physically maintaining the dosing schedule, overcoming side-effects, and recruiting supports and reinforcement for adhering to the regimen. Because 90-95% adherence to highly-active anti-retroviral therapy (HAART) is required for suppression of viral replication in HIV/AIDS patients, and estimates of adherence to HAART range from 57-77%, attention to the issue is critical (Fisher et al., 2006).

Much like research in the HBM and barriers-to-treatment frameworks, the development of the IMB model rests on results of univariate studies on the impact of
one facet of the model or another on adherence. The predictive utility of the complete model with respect to HAART adherence was recently evaluated by Starace, Massa, Amico, and Fisher (2006) and Amico, Toro-Alfonso, and Fisher (2005), whose results support the hypothesis that overall adherence is predicted by information and motivation scores mediated by behavioral skills. Participants in both studies were questioned retrospectively on their recent adherence to their prescribed anti-retroviral medication regimen. Significant correlations between these results and scores on the components of the IMB survey were demonstrated via path analysis. Similar procedures were employed by Robertson, Stein, and Baird-Thomas (2004) who investigated condom use (as a pertinent behavior related to HIV/AIDS) with incarcerated adolescents, and the utility of the IMB in predicting that behavior. Condom use was assessed through retrospective survey, and correlations between this information and scores on IMB survey components were highlighted via path analysis. Results of Robertson et al. suggest the IMB model is useful in predicting condom use in this population.

A full accounting of the predictive validity of the IMB model has yet to be provided as the studies cited here relied on retrospective self-report data on participant health behavior and correlational analyses of relationships between independent and dependent variables. Self-reports are commonly used as a window into patient behavior outside of the direct oversight by a provider in the medical and behavioral health fields, but their accuracy and reliability is often difficult to determine. In the section below on
measurement of adherence, various methods are discussed and the importance of correspondence between self-report and more objective measures is highlighted.

*Theory of Planned Behavior*

The theory of planned behavior (TPB) is less a model of adherence than it is an explanatory framework for behavior born of the inadequacy of dispositional/personality theory to explain complex behaviors in specific contexts (Ajzen, 1991), but as such is an important heuristic to consider in the discussion of adherence. TPB holds that the likelihood of an individual performing any behavior is a function of their intention to perform it, which itself is a function of three antecedent factors: perceived control over the behavior, attitude towards the behavior (along a continuum of unfavorable to favorable), and the importance placed on the behavior by others or the perceived social pressure to perform it.

In a meta-analysis of 185 investigations using the TPB (not limited by discipline, including studies in education, educational psychology, political science, psychology, sociology, public health, and behavioral health) Armitage and Conner (2001) found the model accounted for a significant amount of variance in behavior (27%) and intention to behave (39%). Perceived behavioral control was the strongest predictor of intention (r=.43) compared to attitude and social norms. The model was found to be a robust predictor for observed and self-reported behavior, though it accounted for a significantly greater proportion of variance for self-reported behavior.

The concept of an individual’s perception is arguably the most prominent construct in this framework, as it is in the barriers-to-treatment and HBM models of
adherence (and to a lesser extent in the IMB model of adherence). Perceived behavioral control in the TPB is assumed to vary across situations and behaviors, and is a combination of beliefs about one’s skills, ability to meet requirements such as cost and time, and availability of supports in carrying out the behavior. Perceived social norms with respect to the behavior in question is also predictive of intent to behave in the TPB. The HBM suggests that behavior can be predicted by perception along four factors: susceptibility to illness, severity of illness, benefits of behaving in accordance with recommendations, and the costs associated with it (Becker & Maiman, 1975; Becker et al., 1977). Perceived barriers to participating in treatment are the primary predictor in the barriers-to-treatment model (e.g., Kazdin et al., 1997). Perception of social supports and perception of the quality of the patient-provider relationship are germane to the construct of motivation for carrying out recommended therapy in the IMB model (Fischer et al., 2006). As Azjen (1991) notes, perceived behavioral control is consistent with Bandura’s (1977) conceptualization of self-efficacy – an individual’s judgment of their capacity to perform a behavior. Generally, the more a person perceives he has opportunities and resources required for the behavior, and the fewer obstacles he perceives are in the way, the more likely the behavior is to occur.

Models of Adherence – Summary

Health behavior theories and models provide, at the least, a heuristic within which to understand variation in adherence-related behavior and generate ideas for the enhancement of adherence. There is limited evidence for the general predictive utility and explanatory sufficiency of the models discussed above, and others that have
received attention in the adherence literature such as the transtheoretical model of adherence in addition-related treatments (DiClemente & Prochaska, 1998) and illness perception (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010) calling into question the appropriateness of any individual model of adherence guiding treatment decisions (Munro, Lewin, Swart, & Volmink, 2007). The theory of planned behavior has the broadest base of evidence as an explanatory framework.

As noted above because of content overlap between models (e.g., barriers to treatment is one of the four domains in the health-belief model and is the primary concern in the barriers-to-treatment model; information about treatment costs and benefits is implicated in the HBM and is a key component of the IMB model; and perception of barriers and abilities connects all four frameworks), the models may be tapping into the same or similar constructs within adherence-related behavior. Indeed the same theme has emerged in education research related to adherence (under the heading of ‘teacher program sustainability’ – continued fidelity of program implementation in the classroom after training and support is withdrawn – Han & Weiss, 2005). This research involving comparisons of teacher performance within different intervention contexts suggests that adherence depends in part on the consistency between the content of the intervention and the philosophy of the teacher (e.g., Jennett, Harris, & Mesibov, 2003). That is to say, the perceived relevance of an intervention and its consistency with the beliefs of the teacher is critical with respect to the chances for continued implementation post-training.
A next step in adherence research is to investigate the effectiveness of these models and frameworks individually, collectively, and relatively (Munro et al., 2007), the result of which should be guidance for their use in prescription and practice with targeted disease/disorder populations and the abandonment of models that do not demonstrate this sort of practical utility (Harrison et al., 1992). In a meta-analysis of enhancement procedures for adherence to medical regimens Roter, Hall, Merisca, Nordstrom, Cretin, and Svarstad (1998) found published reports to suggest, on the whole, effectiveness of procedures but found no differential effectiveness between procedures. This result has limited practical utility for at least two reasons: 1) their sample may have been impacted by publication bias towards studies that demonstrate an effect and the likelihood of authors to submit work for publication that includes significant treatment effects (Rosenthal, 1979), and 2) the results were collapsed across treatments stemming from different theoretical models, obscuring which procedures were appropriate under which conditions. Without this information adherence research moves no closer to the goal it should have of enhancing the likelihood of any individual treatment prescriber identifying the correct prescription and supports for their patient or client to maximize the likelihood of adherence to the regimen.

*Measurement of Adherence*

Adherence is a dynamic construct, though often discussed as a dichotomous variable (i.e., adherence or non-adherence). In practice adherence can range from 0 to greater than 100%, if for example extra doses of medication are consumed (Lemanek et al., 2001; Meichenbaum & Turk, 1987). Four distinct patterns of adherence have
emerged from asthma research (e.g., Dirks & Kinsman, 1982; Kinsman, Dirks, & Dahlem, 1980) that may be generally applicable across regimens of prophylactic or therapeutic care: adherent (follows recommendations exactly), overuse, underuse, and erratic (occasional overuse and underuse). The particular pattern of an individual’s non-adherence should be determined prior to recommending adherence enhancement protocol (Farmer, 1999).

These authors and others highlight the need for more than one adherence measure to accurately determine the extent to which a regimen is followed according to recommendations. Rudd (1979) lamented that no single objective, unobtrusive, and practical gold standard measurement method exists. That a gold-standard combination of measures has not been developed may be due in part to ethical limitations on impinging on the privacy of research participants. Most adherence researchers rely on self-report (SR) measures, for which response bias and accuracy are legitimate concerns. To evaluate the reliability of SR measures such as diaries, questionnaires, and interviews, criterion measures (either direct or indirect measures of adherence) have been employed in medical research such as levels of drug in urine (Gordis, Markowitz, & Lilienfeld, 1969), blood pressure (Morisky, Green, & Levine, 1986), pill counts (Stewart, 1987), electronic recordings from blister-pack medication opening (Elixhauser, Eisen, Romeis, & Homan, 1990), and electronic recording of pill bottle openings – the Medical Event Monitoring System (MEMS, e.g., Matsui, Hermann, Klein, Berkovitch, Olivieri, & Koren, 1994). Wetzels, Nelemans, Schouten, Dirksen,
van der Weijden et al. (2007) found MEMS to be an effective tool for increasing adherence, attributing the effect to reactivity relative to the presence of the device.

Garber, Nau, Erickson, Aikens, and Lawrence (2004) conducted a concordance analysis within studies employing SR and criterion measures, finding that SR were highly ($\kappa > .6$, $r > .8$) concordant with non-SR measures in only 43% of studies. Of the SR measures, diaries and questionnaires were more likely than interviews to be concordant with non-SR measures. Of the non-SR measures, electronic measures were least likely to be concordant with SR measures. Of the studies whose measures were not concordant, the SR measure was almost always the higher estimate of adherence. Matsui et al. (1994) support this conclusion in finding MEMS to have been the most conservative of three measures of adherence.

Comparisons of other measures have been made, including Lauritsen, et al. (2006) who compared three self-report methods: electronic diary, telephone diary, and paper diary (which was bound in a book that surreptitiously recorded each time it was opened). The authors found that the highest rates of adherence were reported by paper diary users, but the highest autocorrelations were found in this group as well, suggesting that multiple entries were made at single openings of the binder. Stone, Shiffman, Schwartz, Broderick, and Hufford (2002) also called SR measures into question citing high rates of non-compliance with a recording regimen with paper diaries. Law and King (1993) used several measures of adherence to evaluate which was more likely to predict outcomes for children with cerebral palsy whose parents were responsible for
implementing therapeutic regimens to increase range of hand motion and found that parent SR was the only measure significantly associated with outcome.

Given the limited concordance between SR and objective measures of parent behavior, researchers who rely on SR for information on patient/client behavior in the absence of oversight should not depend on SR alone but seek additional measures as an index of reliability of SR. Questionnaires with demonstrated psychometric properties may be preferred over ad-hoc instruments. For example, Kravitz et al. (1993) constructed the General Adherence Scale (GAS) for use in a study of medical outcomes across disease conditions. The measure contains five items rated on a 6-point scale, with wording of the items designed to capture the extent of internal consistency reliability (Question 1: ‘I had a hard time doing what the doctor suggested to do’; Question 2: ‘I found it easy to do the things my doctor suggested I do’; Question 3: ‘I was unable to do what was necessary to follow my doctor’s treatment plans’; Question 4: ‘I followed my doctor’s suggestions exactly’; Question 5: ‘Generally speaking, how often in the past 4 weeks were you able to do what the doctor told you’). Cronbach’s alpha of .78 indicated acceptable internal consistency reliability of the scale. DeCivita, Dobkin, Ehrmann-Feldman, Karp, and Duffy (2005) reported on the development of the Parent Adherence Report Questionnaire used to measure parent adherence in the context of juvenile idiopathic arthritis, and the evaluation of its psychometric properties. Reliability and construct validity of the measure were supported via similar ratings on repeated administrations (i.e., test-retest reliability), and similar ratings on parallel forms (the GAS and ad-hoc diaries).
Proxy Measures for Adherence: Integrity, Generalization, and Maintenance

When intervention delivery is measured in research involving parents as end-users of recommended treatment protocol, observational measures are often employed and, depending on the stage of treatment, these measures are referred to as treatment integrity or treatment fidelity (during initial stages of the treatment), generalization (after initial success of the treatment has been demonstrated), and maintenance (some time after the last observed treatment administration). Observing end-users implementing treatment at these different stages helps to answer the following related questions. Treatment integrity: ‘CAN you do what I trained you to do?’; generalization: ‘CAN you do what I trained you to do outside of the conditions in which I trained you?’; and maintenance: ‘CAN you still do what I trained you to do earlier?’. The construct of adherence, though related to observational measurement at these three stages of treatment, involves a different question that these researchers have not demonstrated the answer to empirically: ‘DO you do what I trained you to do when I am not present?’

Parents have shown for several decades their ability to be effective behavior change agents for their children. Researchers have measured treatment integrity (e.g., Richman, Hagopian, Birk, Omerod, Brierly-Bowers, et al. 1994; Sanders, 1980) generalization (e.g., Koegel, Glahn, & Nieminen, 1978; Sanders & Glynn, 1981), and maintenance (Eisenstadt, Eyberg, McNeil, Newcomb, & Funderburk, 1993; Eyberg, Funderburk, Hembree-Kigin, McEil, Querido, & Hood, 2001; Long, Forehand, Wierson, & Morgan, 1993) in clinic, home, and community settings. These studies are
consistent with respect to parents’ ability to learn behaviors related to skill instruction for their children. Specific examples include Richman et al. (1994) using a within-subject, multiple baseline design to evaluate the effectiveness of training across three parents in a clinic setting, finding it to be effective in increasing integrity of parent delivery of prescribed responses for child compliance and non-compliance. Similarly, Sanders (1980) found parents learned to attend to appropriate behavior given a treatment package of feedback and self-monitoring.

Research in the phenomenon of child effects is also relevant to the study of parent treatment integrity and the need for careful intervention development given the role of the end-user. Child effects refer to the impact of child behavior on the consistency with which adults implement prescribed programming with acceptable integrity (Carr, Taylor, & Robinson, 1991; Emery, Binkoff, Houts, & Carr, 1983; McConnachie & Carr, 1997). The results of this research (not with parents but with teachers in educational contexts) suggests that adult behavior is sensitive to reinforcement and punishment via the behavior of children (i.e., treatment integrity is systematically reinforced and punished by child behavior). Both Carr et al. (1991) and McConnachie and Carr (1997) found that teachers presented difficult tasks at or above the criterion level for fidelity only when child behavior problems occurred infrequently.

In 1977 Stokes and Baer suggested that if skills are to be used effectively outside of initial training conditions, planning in the training setting and/or some level of treatment in non-training settings is often required. Generalization of skills by end-users is typically seen as necessary for the newly-acquired skills to be meaningful, and
data demonstrating generalization of treatment integrity across contexts, people, or materials, and maintenance of intervention skills and clinical outcomes across time is current best-practice for researchers claiming efficacy of behavior change interventions and the likelihood of success post-training. Sanders and Glynn (1981) evaluated the effects of self-management techniques in promoting generalization for parents of learned skills outside of the training setting, and found self-management strategies were necessary to employ in generalization settings in order for generalization to occur. Koegel et al. (1978) found that parents could learn skills to teach their children a new behavior, but their skills did not generalize to additional new child behaviors without explicit training in the generalization setting.

Research in parent-child interaction therapy (e.g., Eisenstadt et al., 1993; Eyberg et al., 2001; Long et al., 1993) has consistently demonstrated the ability of parents to maintain acquired skills weeks and months post-training. These investigators recognize the critical nature of successful and sustained implementation of effective interventions to suppress child problem behavior. However, parent maintenance of skills in this body of research is measured during clinic visits under direct observation by therapists, leaving the question open as to the use of learned skills in natural environments. Reactivity has been cited as a problem in obtaining accurate measures of behavior via direct observation (Kazdin, 1977), and is a problem not widely understood with respect to its effects in a direct observation measurement system involving parent behavior in situ (for a review of reactivity see Nelson & Hayes, 1981). For example, White (1977) found a 50% reduction in the overall activity level of a family during clinic
observations, but Johnson and Bolstad (1975) reported no differential effects of observation compared to behavior captured on audio tape. The authors acknowledge, however, that parents ‘pressing play’ on recording devices constitutes an intrusion into the environment that may itself cause reactive effects despite its attempt to reduce the impact of the phenomenon.

Parents of Children with Developmental Disabilities

In the developmental disabilities research field, not only are adherence studies absent from the discussion, but the extant knowledge of treatment integrity, generalization, and maintenance has only limited support specific to parent behavior. A search of the literature was conducted using the following terms in the PsycInfo database: developmental disabilities/developmental disorders/mental retardation, parents, adherence/compliance/fidelity/integrity/maintenance; and the Medline database: developmental disabilities/developmental disorders/mental retardation, parents, adherence/compliance. Only one study was returned that met the inclusion criteria of peer-reviewed experimental studies in which parent adherence to treatment was measured (Cunningham, Davis, Bremner, Dunn, & Rzasa, 1993). However, this study examined the behavior of professional teaching parents with their clients in residential homes. Seven additional studies were returned in which parents received training in a variety skills for teaching new behavior and treatment integrity, generalization, and maintenance were measured (Cowart, Iwata, & Poyter, 1984; Feldman, Case, Rincove, Towns, & Betel, 1989; Feldman, Case, Garrick, MacIntyre-Grande, Carnwell, & Sparks, 1992; Huynen, Lutzker, Bigelow, Touchette, & Campbell,
1996; Love & Van Biervliet, 1984; Lowry & Whitman, 1989; Tymchuk & Andron, 1988). Some exceptions are noteworthy: Tymchuk and Andron did not evaluate maintenance of behavior, and Lowry and Whitman evaluated generalization and maintenance by parent description of what they would do given hypothetical teaching situations. Results of these studies uniformly suggest that parents, both with and without disabilities of their own can be effective change agents for their children’s behavior (i.e., implement strategies with acceptable integrity) and can generalize and maintain these skills across time and contexts.

Training and observations of behavior in this group of studies were conducted in participants’ homes, clinic settings, schools, and community environments. Each study included parent training and observations of skills in the environments where their use was ultimately intended. Generally, training and observation sessions occurred weekly, though less frequently during follow-up phases of the investigations. The duration of skills training varied between these studies, as did the schedule of follow-up maintenance observations. Feldman et al. (1989, 1992) conducted scheduled follow-up observations for up to 18 months after the termination of formal training with the mothers in their study who were intellectually disabled, ensuring each mother had sufficient access to support to maintain learned skills. Similarly, Tymchuk and Andron (1988) worked with their participant, a mother with intellectual disability, twice per week for 3 weeks following the end of the training phase of their project. Other investigators chose to conduct maintenance probes less regularly and/or for shorter durations. For example, Huynen et al. (1996) conducted follow-up probes at 2 weeks
and 1, 3, and 6 months post-training in their evaluation of Planned Activities Training (PAT) with four mothers whose children were diagnosed with autism, attention-deficit-hyperactivity disorder, Down syndrome, and risk of developmental delay, respectively. Mothers were trained to prepare and use a variety of antecedent and reinforcement strategies specific to their child and the unique contexts they encounter specifically to prevent the occurrence of challenging behavior. Training occurred in the home, and all four mothers generalized their use of the PAT skills to two or three additional settings around the home or community and maintained their skills at each follow up observation.

Two studies in this group included prescriptions for between-session parent behavior, but data on adherence to those prescriptions were either not reported or not central to the analysis or discussion (Cowart, Iwata, & Poyter, 1984; Love & Van Biervliet, 1984). Cowart et al. (1984) reported the total number of days during which parents practiced adaptive skill instruction with their children. As a group, parents conducted skill instruction on roughly half of the days they were prescribed over a 2-week period. Parents chose 1 skill to work on at home with their child, and did improve on that skill following training. The authors were not clear on the relative contribution of between-session practice to the overall improvement in skill instruction during scheduled observations. Love and Van Biervliet (1984) asked parents to conduct 5 min of reading instruction per day with their children, and log whether or not they followed through each day, but the authors did not report these results.
Toward Adherence Research in Developmental Disabilities

Throughout history therapeutic recommendations have been made for such things as leeching, ice baths, shock, lobotomy, and other procedures to which patients that did not adhere may arguably have been better off (Meichenbaum & Turk, 1987). However, contemporary procedures for positive behavior change have received empirical support within developmental disabilities research generally, and with parents as behavior change agents specifically (Allen & Warzak, 2000). Allen and Warzak and others (Breiner & Beck, 1984; Springer & Reddy, 2004) suggest that empirical evaluations of parent behavior related to therapeutic recommendations outside of treatment environments or oversight by treatment providers are distinctly different from demonstrations that parents can engage in new behaviors related to therapeutic regimens with oversight.

In published accounts of treatment integrity, parent performance as observed by research staff generally occurs under optimal conditions. Parents are aware in advance of scheduled observations, preparations are made to leave sufficient time in the family schedule for the experimenter’s visit to the home or the trip to the clinic, and when observed parents are apt to behave in accordance of the expectations of the observer (i.e., reactivity). Observed integrity of treatment implementation under these conditions, then, is not necessarily suggestive of adherent behavior under naturally-occurring conditions. By investigating the level of integrity required to achieve or maintain clinically meaningful outcomes at home (Arkoosh et al., 2007) in inpatient settings (Northup, Fisher, Kahng, Harrel, & Kurtz, 1997), and at school (Sterling-Turner,
Watson, & Moore, 2002; Vollmer, Roane, Ringdahl, & Marcus, 1999; Wilder, Atwell, & Wine, 2006), several authors have begun to question ‘how much treatment integrity is enough’, assuming that end-users of behavior change technology will not implement with perfect integrity. Emerging results suggest that level of integrity is indeed related to observed clinical outcome. Arkoosh et al., Northup et al., and Vollmer et al. found child behavior may be robust to deterioration in treatment integrity, and more specifically that it is robust even as integrity of intervention strategies in response to problem behavior deteriorate considerably as long as relatively higher levels of integrity of proactive and reinforcement strategies are maintained. It is noteworthy that Arkoosh et al. included parents as end-users of the behavioral protocol, while the other investigations worked with teachers or clinical staff.

Allen and Warzak’s (2000) call for a thorough behavior analysis of adult behavior in the context of adherence to treatment echoed the empirical reality in the medical community that demonstrations of treatment integrity not only are insufficient to suggest that learned skills are practiced appropriately or effectively in the absence of oversight, but also insufficient for understanding the patterns of adherence (including antecedents and consequences) related to optimal and sub-optimal clinical outcomes. These authors join with others in the behavior therapy field generally (Springer & Reddy, 2004) and developmental disabilities field specifically (Breiner & Beck, 1984) to measure between-session behavior as a more robust indicator of what parents are likely to do given recommended treatment in the absence of oversight. To date only one related clinical demonstration has been published (Fleischman, 1979), in which parents
were trained to implement positive reinforcement and time-out for the management of problem behavior and instruction of habilitative skills. Parents telephoned a therapist each day to report their use of strategies and data on child behavior. The treatment in effect for parents was a salary for implementing the intervention as planned, which was found to interact with family type on the outcome of adherence to recommended treatments (which Fleischman termed ‘cooperation’) such that lower income-single parent families were more cooperative in the presence of a salary, and higher income-two parent families were cooperative regardless of salary. Unfortunately Fleischman evaluated only parent reported use of strategies, not adherence to the daily phone calls, and did not analyze or discuss differential reported use of recommended strategies.

The need for adherence research has been identified by investigators studying children with autism and their families (e.g., Charman & Howlin, 2003; Moore & Symons, 2009) who point out that parents of children with autism spectrum disorders (ASD) are commonly charged with carrying out behaviorally-based recommendations to promote skill acquisition and manage problem behavior (Kashinath, Woods, & Goldstein, 2006), as well as administering medications for the management of challenging behavior (Aman, Lam, & Collier-Crespin, 2003; Arnold, Vitiello, McDougle, Scahill, Shah, Gonzalez, et al., 2003). Empirical findings with respect to adherence and non-adherence in autism research will be important given the growing incidence of autism (CDC, 2010) and associated clinical options available to families.
Chapter III. Method

Participants.

Following University of Minnesota IRB approval, a paper copy of an ad hoc treatment adherence survey (see Appendix B), along with a passive consent document, was sent to parents who had completed or were currently participating in the General Interaction Strategies (GIS) parent training curriculum as clients of a community-based provider of early intensive behavioral intervention (EIBI) for children with autism spectrum disorders and associated family supports (n=61). Each family’s child was receiving EIBI at the time the parents received GIS training. Families lived in or near major metropolitan areas in the Midwest. The survey was hand-delivered to parents whose children were still receiving EIBI services from the provider (n=49, parents may or may not have been receiving GIS training at that time), and was mailed to families no longer receiving any provider services (n=12). Parents were asked to complete and return the survey in a self-addressed, pre-paid envelope. Parents to whom the survey was delivered by hand were told that their answers to the survey questions would not be made available to clinical staff, that only research staff would have access to the information. Inclusion criteria for respondents were: 1) prior or current receipt of GIS training, 2) survey returned by a cutoff date, selected a priori, approximately 6 weeks following survey distribution.

‘General Interaction Strategies’ Parent Training Curriculum

Parents were taught, in their home, six basic behavior management skills for use in everyday routines with their children. Each skill consisted of 2-6 components. The
skills were establishing reinforcers, offering choices, delivering instructions, honoring requests, redirecting minor challenging behavior, and responding to major challenging behavior. Training for each skill began with parents (generally mothers alone were the targets of training, though fathers participated in some cases) completing a 2-3 page reading on the behavioral principles underlying the skill. They then completed a brief worksheet containing 5-10 questions capturing the main content ideas and generated suggestions for application of the content to their child. A trained GIS trainer (minimum bachelor’s level clinician with supervisory responsibilities within the organization) reviewed the reading and worksheet with parents, and worked with the parents to identify target behaviors and applications of the content to the child. The trainer then provided most-to-least intrusive supports (primarily verbal prompts for language and gestural prompts to use materials) for the parents to use the skills with their children. Two consecutive sessions with 80% independent performance was criterion for mastery of each skill component. Skills were taught in serial (i.e., mastery of one skill triggered the instructional process for the following skill) and in the same order with each family. GIS training occurred 1-2 days per week. A list of the six GIS skills and their components is provided in Appendix C.

Construction and Description of Survey.

Seventeen survey items were arranged in four sections: 1) Using the General Interaction Strategies (adherence), 2) Your Family (family characteristics), 3) Your Child (child characteristics), and 4) You and Your Spouse/Partner (characteristics of the parental relationship). The complete survey is available in Appendix D. In the first
section, parents checked a box corresponding to the extent to which they adhered to each of the six categories of general interaction strategies they were trained to use (Questions 1-6). Question 7 asked parents to identify reasons why they may not have adhered perfectly to the strategies they were trained to use. The answer to this question provided information on the internal consistency of the measure. First, if a family reported less than perfect adherence on Questions 1-6, a minimum of one box should have been checked as an explanation of why adherence was not optimal. Second, answers to this question were designed to correspond to answers on Questions 8-11. To the extent answers to Question 7 corresponded to answers to Questions 1-6 and 8-11, the measure was internally consistent.

In the second section of the survey, Questions 8-11, parents checked a box corresponding to the best answer to questions about social supports for the family, perceived efficacy using the GIS, likely future results for the child based on using the GIS, and acceptance of the child by family and community. In the third section of the survey parents identified the age of their child when he or she was first diagnosed with an ASD, checked boxes to indicate problem behaviors their child exhibited, and checked a single box to indicate their perceived level of difficulty in managing problem behavior. In the fourth section of the survey parents checked a box representing the extent to which they agree on intervention decisions with their spouse or partner, their highest level of education, and whether they had ever been diagnosed with a mental illness and/or developmental disability. These items were included based in part on the work of McWilliam (2001), Remington (2010), and Solish and Perry (2008) suggesting
their importance in parent engagement in provision of services to their children. Other family and child characteristics included on the survey, and culled from existing records for data analysis (described below) were selected based on their importance in adherence research in medicine (e.g., Meichenbaum & Turk, 1987) and behavioral health (e.g., Kazdin, 1997). An initial draft of the survey was reviewed with the research committee of the service delivery agency through which this project was conducted. Recommended adjustments to wording and question order were made, and the survey was presented to families as described above.

Design and Analysis.

Data collection for this study involved a single time point anonymous survey design with no follow-up. Survey results were initially analyzed via descriptive statistics (frequency counts, percent occurrence, ranges). Responses to each survey item were assigned values prior to analysis, with higher numbers corresponding to greater adherence, greater perceived support and efficacy, higher educational attainment, parent agreement on intervention implementation, and lesser mental health or developmental disability rating for parents.

Each potential predictor of adherence was entered into a correlation matrix as an independent variable with overall adherence, and adherence to each individual intervention category, as dependent variables. Potential predictors were derived from survey report or existing clinical record and included marital status, agreement with spouse on when and how to implement the GIS interventions, level of parent education, parent mental health history, number of children living at home, child diagnosis, age at
diagnosis, whether the family was currently being served by the provider agency, total number of problem behaviors, perceived level of difficulty of those behaviors, total perceived barriers, perceived support from family and friends, perceived effectiveness as an agent of behavior change, perceived confidence in the GIS to produce meaningful behavior change, and perceived acceptance of the child in family and community activities.

Those that correlated significantly with any dependent variable were entered into a regression analysis to evaluate the extent to which specific independent variables were associated with reported adherence. In the initial model none of the four individual independent variables significantly explained variance in reported adherence. Exploratory factor analysis and correlations between predictors were used to create a single variable from three of the predictors, which was then used in the final regression analysis.
Chapter IV: Results

The following research questions were asked in the current investigation: 1) what family, parent, or child characteristics were associated with reported adherence by parents of children with ASD to behavior change skills they mastered during in-home training, 2) to what extent were parent perceptions of their own effectiveness, social supports, and acceptance of the child into community and family, as well as confidence in the intervention to produce meaningful outcomes, associated with reported adherence, and 3) to what extent was treatment integrity, as indexed by sessions-to-criterion, predictive of reported adherence?

**Descriptive Statistics- Question 1**

A total of 21 surveys were returned (34%). Family characteristics are presented in Table 1. Information gathered from company records indicate 85% were married and had a range of 1-4 children living at home. According to survey reports, 95% of respondents had completed at least some college education (38% had post-graduate experience), 10% reported a history of mental illness, 19% reported agreeing with their spouse about treatment implementation decisions ‘less often than not’ or ‘not at all’, 48% reported agreeing ‘more often than not’, and 29% reported agreeing with their spouse ‘almost always’.

Of the 40 non-responders, a random sample of 21 was selected for which available information on family characteristics was gathered (marital status and number of children living at home). Responders and non-responders did not differ significantly
on either variable according to a t-test of independent samples (p<.74 for marital status, p<.95 for children at home).

Child characteristics are presented in Table 2. According to company records autism was the most frequent diagnosis (48%), followed by Autism Spectrum Disorder (ASD – 24%), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS – 19%), and Disruptive Behavior Disorder (5%). Age at diagnosis ranged from 15-48 months. Parents reported the current occurrence of aberrant behaviors on the survey (range 1-6), including aggression, self-injury, physical disruption, verbal disruption, tantrums, and non-compliance, with difficulty ranging from ‘not at all’ (5%) to ‘slight’ (43%), moderate (43%), and ‘very’ (10%).

Descriptive Statistics-Question 2

Barriers to adherence are presented in Table 3. Parents reported several barriers to adherence if they indicated imperfect adherence to any of the six GIS skill areas (range 1-6). They also reported specifically on their perceptions of support from family and friends, effectiveness as agents of behavior change, confidence in the GIS strategies, and acceptance of their child in family and community. A minority of parents (29%) reported ‘little’ or ‘no’ support, 52% reported ‘moderate’ support, and 19% reported a ‘great deal’ of support. Nearly half of parents (48%) reported being ‘very effective’ agents of behavior change, 43% reported being ‘moderately’ effective, while 9% reported being ‘slightly’ effective. All parents reported feeling a ‘great deal’ or a ‘moderate’ level of confidence in the GIS strategies producing meaningful results over time (86% reported a ‘great deal’ of confidence). A wider range of responses were
provided for perceived acceptance of the child in family and community activities, with 43% of parents reporting their child is ‘very well accepted’, 38% reporting a ‘moderate’ amount of acceptance, and 19% indicating their child is ‘slightly’ accepted.

*Descriptive Statistics - Question 3*

As a function of the type of the archived GIS data, integrity of parent implementation of the GIS was indexed by sessions-to-criterion mastery performance (which was 80% integrity in two consecutive sessions). Of the 21 adherence surveys returned, 13 GIS data sets were available for analyses. Bivariate correlations were computed between available integrity data for each GIS skill and the parent-reported adherence on that skill. It was expected that correlations would be negative – i.e., fewer sessions required for mastery would be associated with greater reported adherence. No correlations were significant, (but some were in the expected direction and some would be considered large and possibly significant with greater sample size): identifying a reinforcer ($\rho = -.46$), offering choices ($\rho = -.02$), delivering instructions ($\rho = -.01$), honoring requests ($\rho = .24$), redirecting minor disruptive behavior ($\rho = .63$), and responding to upsets ($\rho = -.61$).

*Reporting Consistency*

To estimate the consistency of parent report, the proportion of respondents who indicated imperfect adherence (Questions 1-6) to those who indicated at least one barrier to adherence (Question 7) was calculated. The majority of respondents who indicated imperfect adherence also noted at least one barrier to adherence in Question 7 ($20/21 = .95$). Similarly, no parents who cited support as a barrier to adherence in
Question 7 indicated they had a ‘great deal of support’ in Question 8 (0/4=.00), and only one parent who did not cite support as a barrier to adherence in Question 7 indicated ‘no support’ from family and friends in Question 8 (1/17=.06). Finally, a small proportion of parents (3/18=.17) indicted they had a ‘great deal of confidence in the GIS producing meaningful results on Question 8 but also cited limited meaningful results produced by the GIS in Question 7.

Correlations Among Predictors

There were a number of significant correlations among predictors (see Appendix D). Level of agreement between spouses on when and how to implement interventions was positively correlated with perceived effectiveness as a change agent and with perceived confidence in the GIS strategies to produce meaningful change. Number of children in the home was positively correlated with total perceived barriers. Child diagnosis was negatively correlated with age of diagnosis (children with autism tended to be diagnosed when older than children with PDD-NOS, ASD, or disruptive behavior disorder). Total behaviors was positively correlated with perceived difficulty in managing those behaviors and negatively correlated with perceived effectiveness as an agent of behavior change. Perceived effectiveness and confidence in GIS producing meaningful outcomes were positively correlated.

Correlation Between Predictors and Outcomes

Four predictors were significantly positively correlated with the outcome of average adherence: agreement with spouse ($\rho = .51$), perceived effectiveness as a change agent ($\rho = .58$), perceived confidence in the GIS producing meaningful
outcomes ($\rho = .55$), and perceived acceptance of the child in family and community activities ($\rho = .53$). One predictor (total reported barriers to adherence) was significantly negatively correlated with the individual adherence score for honoring requests ($\rho = -.53$). Correlations between the average adherence score and the individual adherence scores were each significantly positively correlated (range $\rho = .56 - .83$).

Factor Analysis

Bivariate correlations between agreement with spouse, effectiveness, and confidence were significant (see Appendix D) and the association of the three measures taken together was high ($\alpha = .71$). Additionally, each item was correlated significantly with at least one adherence outcome. To examine the possibility the three variables represented a single construct they were entered into an exploratory factor analysis (principal component analysis) and found to all load on a single factor. The eigenvalue for the single factor solution was 2.02, with factor loadings of .42 (agreement with spouse), .40 (effectiveness and confidence). While the subject-to-variable ratio in this factor analysis was 20:3 (or 6.7:1) is considered by some to be acceptable (Bryant & Yarnold, 1995), others (Cattell, 1978) consider much higher ratios or sample sizes necessary to identify common factors from otherwise independent variables. For the purposes of this analysis the identification of a new factor (‘assurance’) should be considered tentative. This factor was created for use in a subsequent regression analysis by calculating the sum total score for the three variables.
Regression Analysis

The aggregate variable ‘assurance’ was entered into a linear regression model with perceived acceptance of child in family and community activities. This analysis examined the extent to which these variables predicted average reported adherence to treatment. The model was predictive for reported adherence to treatment (p < .001) and explained 53% of the variance (adjusted $R^2 = .53$). The assurance variable explained 36% of the variance (p < .002) while acceptance explained 10% (p < .07).

The four primary assumptions of linear regression were met based on analysis of the data collection methods and the diagnostic plots provided in Appendix C. The data can be considered free of serial dependence because each family provided a single data point for each independent and dependent variable and were not influenced by the performance of other families. The standardized residuals of the dependent variable are normally distributed per the histogram. A linear relationship between the dependent and independent variables is apparent per the scatterplots. Equality of error variances is evident given the scatterplot of residuals against predicted values.
Chapter V: Discussion

The current study is the first to address parent adherence to ABA-based treatment recommendations in the context of a known intervention delivered by a single provider organization. The study is also the first to explore the relationship of adherence to family, parent, and child characteristics, as well as social/perceptual factors previously shown to be associated with adherence and related engagement behavior of parents. The first set of research questions asked what family, parent, or child characteristics were associated with reported adherence by parents of children with ASD to behavior change skills they mastered during in-home training. Results suggest the most important characteristic is that of the extent of agreement between married couples on how and when to implement intervention strategies. This is a logical result for at least two reasons. First, it holds that enhanced agreement between multiple implementers of a protocol would lead to greater overall adherence to that protocol. Second, parents must make similar decisions with respect to their children and families regardless of the characteristics of each. That is to say, parents decide how to handle problem behavior no matter how many different topographies are exhibited or how intensely they are displayed, no matter how many children they have, and regardless of their personal dispositional or state variables. Parents choose how to conduct the affairs of their households and the extent to which the system of operation is mutually agreed upon it stands to reason that the system will be consistently administered.

The second question asked to what extent parent perceptions of their own effectiveness, social supports, and acceptance of the child into community and family,
as well as confidence in the intervention to produce meaningful outcomes, were associated with reported adherence. Two variables based on the second research question played a role in the final analysis along with the variable ‘spousal agreement’. ‘Perceived effectiveness’, ‘confidence in the intervention strategies to produce meaningful outcomes’ and ‘spousal agreement’ loaded onto a common factor named ‘assurance’ accounting for a significant portion of the variance (58%) in the regression model. Perceived acceptance was not a significant predictor at the conventional .05 level in the regression model, but was associated as indexed by significant bivariate correlations with average adherence and two of the component adherence skills, choice and instruction delivery. This finding lends support to the construct of perception as a common thread in models of adherence. Perception is a key component in the Health Belief Model (Becker et al., 1977), the Information-Motivation-Behavioral Skills model (Fischer et al., 2006), the Barriers to Treatment model (Kazdin et al., 1997), the Theory of Planned Behavior (Ajzen, 1991), Bandura’s (1977) model of self-efficacy, and the analysis of family systems specific to children with disabilities (Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005).

The third question asked to what extent treatment integrity is predictive of reported adherence. The available data (13/21 possible) suggest no significant relationships between integrity and adherence, although three of the six correlations (identifying a reinforcer, ρ = -.46; redirecting minor disruptive behavior, ρ = .63; and responding to upsets ρ = -.61) were substantial although non-significant (likely as a function of a small sample size). Logically, integrity and adherence are related
constructs and the exact nature of this relationship will require explication through focused attention in future research. Specifically, what dimensions of integrity are related to adherence – strength of implementation, sessions to criterion performance, or perhaps duration of practice under supervision?

This investigation extends the work of Moore and Symons (2009) and ads to the adherence research literature in several ways. First, it supports the concept of parent perception as a critical factor to consider in planning for adherence to interventions. The descriptive results suggested that four variables related to perception were associated with adherence: agreement with spouse on when and how to implement interventions, perceived effectiveness as a behavior change agent, confidence in the intervention to produce meaningful results over time, and perceived acceptance of the child by family and community. The first three of these variables may reflect a single underlying construct. Referred to as ‘assurance’ in the current study, this construct may reflect the relationship between parent alignment on treatment for their child, confidence that the treatment will produce meaningful results, and the perception of effectiveness as behavior change agents. Parent assurance in the proper way forward in handling complex child behavioral excesses and skill deficits may include these three elements and be critical for clinicians to consider when designing interventions with families.

Second, these results were generated by a sample of parents from a known population who received a common skills training intervention delivered by a single service provider. Therefore several variables were known to the experimenters that were unknown to Moore and Symons: 1) specific treatment recommendations (establishing
reinforcement, offering choice, delivering clear instructions, honoring requests, responding systematically to minor and major disruptive behavior), 2) type of clinician making the recommendation (program overseen by licensed psychologist, developed and maintained by masters-level Board Certified Behavior Analysts, and delivered by minimum bachelor’s-level clinicians at a supervisory level within the provider organization), and 3) the type of training provided during acquisition of skills (behavioral skills training including modeling, verbal prompting, and fading procedures). Third, the range of identified characteristics of family, parents, and children in the current survey was expanded beyond that gathered by Moore and Symons, and addressed potential reasons for non-adherence directly connected to existing models of adherence and frameworks for behavior. Fourth, the survey used in the current study was designed to provide more information on internal consistency reliability. Data suggest respondents were consistent with their answers across questions with shared content.

An unexpected finding in the current investigation was the absence of a relationship between diagnosis and adherence, such as that found by Moore and Symons (2009). Specifically, Moore & Symons results suggested that parents of children with Asperger’s disorder reported significantly lower adherence than parents of children with autism. According to record reviews, no child in the current sample was diagnosed with Asperger’s disorder, but the pattern could arguably have been expected to replicate with children diagnosed with PDD-NOS and/or ASD. It may well be that children diagnosed with Asperger’s disorder are systematically different than those whose
children have other pervasive developmental disorders, or children with Asperger’s disorder may behave in systematically different ways towards their parents than children with other pervasive developmental disorders. Exploring systematic differences among diagnostic categories within what are currently known as the pervasive developmental disorders (American Psychiatric Association, 2000) may not be fruitful in the long term given that the American Psychiatric Association has proposed collapsing autism, Asperger’s disorder, and PDD-NOS into a single diagnosis of ‘autism spectrum disorder’ per the draft copy of the 5th Edition of the Diagnostic and Statistical Manual. Perhaps more relevant to the discussion of differential parent adherence to behavioral treatment recommendations is the parent experience during training (including the quality of the relationship with the trainer) and the realities on the ground that remain after training is completed and therapists go home. Especially relevant to the latter point is the nature of the discriminative stimuli left in place by the trainer. If parents are reliant on the presence of the trainer to behave in accordance with the treatment, rather than naturally-occurring discriminative stimuli, they may be less likely to persist (Marholin, Steinman, McInnis, & Heads, 1975).

Going forward, measurement of adherence to behavioral treatment recommendations in developmental disabilities research should evolve to capitalize on the detail available through parent self-report and the accuracy of direct observation methods, while minimizing the bias inherent in both. First, it is common practice in observational research to ensure consistency of individual observer reports and reliability of reporting from multiple observers (Kazdin, 1977). Investigators may wish
to use competency-based procedures when working with parents to ensure their observations are consistent and reliable prior to expecting accurate reports in natural contexts (e.g., quantitative data, narrative diaries, retrospective interviews, retrospective surveys), which themselves should be subject to regular reliability checks throughout the duration of an investigation (Chamberlain et al., 1984).

Second, given self-report estimates of behavior often exceed estimates generated by objective measures (e.g., Matsui et al., 1994), it will be critical for adherence researchers in developmental disabilities to become familiar with and evaluate (and perhaps develop) objective measures. Advances in the medical research literature should be informative (e.g., electronic diary recording, Lauritsen et al., 2004), and the practice of investigating concordance between self-report and objective measures (Garber et al., 2004) should become best practice. Other technological advances in recording and measurement should be considered for their potential not only as objective measures of adherence but also as means to reduce the reactive presence of observers. For example, the LENA (Language Environment Analysis) vocal output analysis system is a promising new tool for the capture of vocal speech without an experimenter present (Warren et al, 2010). The software recognizes speakers and can analyze frequency of utterances as well as turn-taking. Another available option is video cameras with built-in microphones – many are available that provide 360° views of rooms and have been used successfully by researchers monitoring the behavior of participants at remote sites (Pindiprolou, Peterson, Rule, & Lignuaris-Kraft, 2002). Others can be operated by remote control via the Internet. Fleischman (1979) made use
of simpler technology, requiring parents to make daily phone reports of their data. This approach could be extended by having therapists call parents at randomly-selected points throughout the day and report relevant programming and behavioral information.

Limitations

This survey study relied on descriptive information to inform initial and tentative conclusions about the relationships between several independent variables and the dependent measure of adherence to treatment. Power in the factor analysis and regression analysis were limited due to small sample size, an issue which future research should address while continuing to tightly specify population parameters. It would be inappropriate to make definitive causal claims about causal relationships between the factor of ‘assurance’ and the likelihood of parent adherence to treatment, but the current results should be considered by future researchers as a benchmark against which to compare new and related data. A critical limitation with respect to the external validity of the results is the potentially biased sample. A large majority of respondents (95%) had at least some college education with 38% reporting post-graduate experience. The responses provided by this sample may be systematically different from those a more diverse sample with respect to educational history might report.

Researchers who study parent adherence to behavioral treatments in the future should also consider extending the theoretical limitations of the current study. Theoretical models and frameworks for adherence and related behavior such as the HBM, IMB, Barriers to Treatment, and Theory of Planned Behavior should be studied
within prospective designs to not only further delineate predictive utility but also evaluate adherence enhancement procedures following determination of status within the framework of the model (i.e., to what extent is the knowledge of an individual’s status within the TPB useful in development of adherence enhancement procedures, and to what extent do those procedures enhance adherence?). Second, parent perception should be evaluated further to understand its relationship to other constructs such as stress, belief, self-efficacy, and rule-governed behavior understood currently through the work of Hastings and colleagues (2005), Remington (2010), and Solish and Perry (2008) to impact the likelihood of parents engaging in therapeutic behaviors. Third, developmental disabilities researchers should consider adopting practices from other disciplines (e.g., behavioral health) who typically collect parent scores on standardized tests and other demographic scales (e.g., Kazdin et al., 1997; MacNaughton & Rodrigue, 2001), and expand their own practice of reporting on the cognitive characteristics of parents in their studies (Feldman et al., 1992; Feldman et al., 1989; Tymchuk & Andron, 1988). Mediating or moderating relationships may emerge between these characteristics, adherence-enhancement procedures, and adherence itself, further serving to specify treatment parameters for specific subsets of parents. Additionally, standardized measures with demonstrated psychometric properties may be preferred over ad-hoc surveys used in the current investigation. Fourth, behavior analyses of adherence should be conducted to advance understanding of the contextual, antecedent, and consequent events associated with parent adherence and non-adherence (Allen & Warzak, 2000). Finally, research addressing level of treatment integrity
required for a meaningful clinical outcome, and the relationship of integrity to adherence, should be examined across a variety of behaviorally-based interventions, parents who implement them, and the range of abilities and disabilities of their children (Arkoosh et al., 2007; Northup et al., 1997; Small, 2007; Sterling-Turner et al., 2002; Vollmer et al., 1999; Wilder et al., 2006).

The multitude of research directions proposed above are important to address in equal measure because they are in service of uncovering what works to enhance the likelihood that professionals will strive to form effective partnerships with the unique families in their care, individualized and effective interventions will be developed, and parents will adhere to treatments to produce lasting change. In the end, treatment occurs within a family context (Harris, 1984) and involving family members in treatment planning (including an informed decision of whether their child should participate in a given treatment) and treatment delivery may function to enhance or dull the impact of any intervention focused on an individual with a disability (Bailey et al., 1998). Moving forward in the comprehensive support of individuals with developmental disabilities and their families will require building interventions with families, not for them, understanding what parents perceive to be important and effective, maximizing available support in service of consistent participation, adherence to treatments that produce results, and ultimately the outcomes families and their supporting professionals strive to achieve.
References


Centers for Disease Control (2010). Autism spectrum disorders: what should you know? Retrieved from Centers for Disease Control website:


Rudd, P. (1979). In search of the gold standard for compliance measurement. *Archives of Internal Medicine*, 139 (6), 627-628.


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Table 2. Child characteristics

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A=aggression, S=self-injury, PD=physical disruption, T=tantrum, VD=verbal disruption, NC=non-compliance
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</table>

*p<.05; **p<.002, p<.001***
Appendix A.

Survey

Using the General Interaction Strategies

1. How consistently do you establish reinforcers before activities?
   - 100% of opportunities
   - 80% - 99% of opportunities
   - 50 - 79% of opportunities
   - 1% - 50% of opportunities
   - Never

2. How consistently do you offer choices instead of making demands?
   - 100% of opportunities
   - 80% - 99% of opportunities
   - 50 - 79% of opportunities
   - 1% - 50% of opportunities
   - Never

3. How consistently do you give instructions as taught by your General Interaction Strategies trainer?
   - 100% of opportunities
   - 80% - 99% of opportunities
   - 50 - 79% of opportunities
   - 1% - 50% of opportunities
   - Never

4. How consistently do you honor your child’s requests when you can, and provide alternatives to their request when you cannot?
   - 100% of opportunities
   - 80% - 99% of opportunities
   - 50 - 79% of opportunities
   - 1% - 50% of opportunities
   - Never

5. How consistently do you use redirection techniques as taught by your General Interaction Strategies trainer?
   - 100% of opportunities
   - 80% - 99% of opportunities
   - 50 - 79% of opportunities
   - 1% - 50% of opportunities
   - Never
6. How consistently do you respond to challenging behavior as taught by your General Interaction Strategies trainer?
- 100% of opportunities  N/A – not yet trained
- 80% - 99% of opportunities
- 50 - 79% of opportunities
- 1% - 50% of opportunities
- Never

7. If you indicated in any question above (1-6) that you follow through with the General Interaction Strategies in less than 100% of opportunities, what are some reasons why? (check all that apply - please write in your answer(s) if not listed)
- They are too difficult or intensive
- They are not effective for producing meaningful results
- I don’t have support from friends and family
- I believe that different clinical approaches are more appropriate to use with my child
- I sometimes do not have the energy to be consistent
- They are not consistent with the values system of my family
- Other

Your Family

8. How much support do you feel you have from friends and family for your use of these behaviorally-based strategies?
- A great deal of support
- A moderate amount of support
- A little bit of support
- No support

9. How effective are you currently at producing meaningful behavior change by using the General Interaction Strategies?
- Very effective
- Moderately effective
- Slightly effective
- Not at all effective

10. How much confidence do you have that using the General Interaction Strategies will produce meaningful results for your child in the future?
- A great deal of confidence
- A moderate amount of confidence
- A little bit of confidence
- No confidence
11. How well-accepted is your child in family and community activities?
   - Very well accepted
   - Moderately accepted
   - Slightly accepted
   - Not at all accepted

**Your Child**

12. How old was your child when he or she was first diagnosed with a developmental disorder?

13. Currently, what problem behaviors does your child exhibit *(check all that apply)*?
   - Aggression
   - Self-injury
   - Property destruction or other physical disruption
   - Tantrums / meltdowns
   - Verbal disruption (e.g. bossing others, screaming)
   - Non-compliance (e.g. refusing food, bedtime, other demands)

14. How difficult is it for you to manage your child’s problem behaviors?
   - Very difficult
   - Moderately difficult
   - Slightly difficult
   - Not at all difficult

**You and Your Spouse/Partner**

15. How often do you agree with your spouse/partner on when & how to implement General Interaction Strategies?
   - Almost always
   - More often than not
   - Less often than not
   - Not at all

16. What is your highest level of education (the primary recipient of General Interaction Strategies training)?
   - Some high school
   - High school
   - Some college
   - College
   - Post-graduate

17. Have either of you, the primary caregivers of your child, ever been diagnosed with a mental illness or an intellectual disability?
   - Yes, a mental illness
   - No, neither
   - Yes, an intellectual disability
Appendix B.

General Interaction Strategies curriculum.

Parents are taught the following skills:

1. Establishing reinforcers
   a. Parent identifies an item or activity to use as a reinforce prior to giving an instruction or having child complete a task
   b. Parent places emphasis on reinforcement versus the task the child will complete when giving the instruction
   c. Parent delivers reinforcement and praise if/when child follows through with instructions
   d. Parent physically guides child to comply with instructions if they have not complied with the instruction or need assistance to complete the instruction within 2-3 seconds

2. Offering choices
   a. Parent offers child choices of preferred activities or items when they are engaging in appropriate behaviors
   b. Parent offers appropriate alternative behaviors using a choice between 2 items/activities when child is exhibiting disruptive behaviors
   c. Parent offers choices of 2-3 items/activities/actions if a child is not responding to an open-ended choice of activities

3. Giving instructions
   a. Parent gets child’s attention prior to giving an instruction
   b. Parent gives instructions using specific, short, concise statements
   c. Parent delivers the instruction only a single time
   d. Parent delivers reinforcement following naturally-occurring appropriate behavior
   e. Parent delivers reinforcement when child follows instructions given by parent

4. Honoring requests
   a. Parent acknowledges appropriate child requests
   b. Parent begins the process of honoring the request immediately
   c. Parent tells child when they will be able to have access to requested items/activities if not immediately available
   d. Parent tells child immediately if requested items/activities are entirely unavailable, and offers fun alternatives
e. If request is made using a disruptive voice, parent tells child “I’ll talk to you when you are calm” or a similar statement. Parent does not honor request until it is restated in appropriate voice/tone.

5. Redirecting off-task or mildly-disruptive behaviors
   a. Parent attempts to engage child who is off-task by one of the following interactive strategies: prompt communication, establish reinforce and deliver sD for mastered responses, hand child activity/object, physically guide to begin activity
   b. Parent attempts to engage child who is off-task by one of the following non-interactive strategies: begin activity in sight of the child, put activity in near vicinity/sight of the child

6. Responding to upsets/challenging behaviors
   a. Parent discontinues interactions when child is engaged in disruptive or challenging behavior
   b. Parent does not make eye contact with the child during an upset
   c. Parent remains neutral during an upset
   d. Parent does not offer choices or give instructions to the child during an upset
   e. Parent approaches the child when calm/quieting down and reinforces this behavior by making a statement, re-engaging the child in an activity with them, or other reinforce
   f. Parent follows through with any instructions given prior to the upset
Appendix C.

Regression diagnostics.
Scatterplot

Dependent Variable: AvgAdherence
## Appendix D.
### Correlation Matrix

The table below shows the correlation matrix for various variables. The matrix is sorted by Spearman's Rho, indicating the strength and direction of the relationship between variables.

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<td>-0.071</td>
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<td>-0.175</td>
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<td>0.075</td>
<td>0.000</td>
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*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).