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Community services outcomes for families and children with autism spectrum disorders

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Abstract

In an era in which evidence based practices are becoming the standard of care, there is little evidence that the current array of services commonly delivered for those with autism is helpful. This study describes community-based service utilization and caregiver-rated outcomes of services on symptoms of 113 children with autism spectrum disorders and their families. Parents/caregivers reported on nine types of services, received in the prior 6 months, which were evaluated against child and family outcomes. Caregivers rated in-home behavior therapy as providing the best outcomes overall for the child and respite care as providing the best outcomes for the family. Younger children were reported to have better outcomes than older children. Polytherapy was the rule, rather than the exception, as children used a mean of 3.5 different services. The frequency of services and the number of different types of services utilized correlated with family but not child outcomes. Examination of the potentiating effect of medication on outcomes of psychosocial interventions was not significant.

Keywords: Autism spectrum disorders; Service outcomes; Community-based services; Child outcomes; Family outcomes

1. Overview of community services

Little is known about the services used by children with autism spectrum disorders (ASD). What is known is that children and families of those with ASD participate in a vast array of services delivered by multiple agencies, professionals, and funding sources (Goin-Kochel, Myers, & Mackintosh, in press; Liptak, Stuart, & Auinger, 2006; Thomas, Ellis, McLaurin,

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Daniels, & Morrissey, 2006). For example, Thomas et al. (2006) surveyed a community sample of 383 families with a child with ASD 11 years or younger and found that on average, children and families utilized four different types of services outside the school system (e.g., medical services, biomedical treatments, speech and language therapy, occupational therapy, behavior intervention, respite care, social skills therapy, family counseling, and case management) and Goin-Kochel et al. (in press) found in their survey of 479 parental reports that children received between 4 and 6 different treatments simultaneously. Similarly, Kohler (1999) found that on average children received services from four different types of agencies delivered by more than seven different professionals (e.g., early intervention agencies, primary care clinics, tertiary care centers, community mental health centers, Medicaid waiver agencies, and private pay providers). Compared to children in general, children with autism used more outpatient visits, physician visits and medications according to a recent study by Liptak et al. (2006).

Although there are preliminary data concerning the array of services accessed by families of children with autism, there are almost no data concerning the helpfulness of those services as delivered in the community, either experimentally or as rated by users of the services. For example, studies when available typically have been restricted to the examination of a single service, even though polytherapy is the rule (Goin-Kochel et al., in press) rather than the exception with ASD. Although this information shortfall is perhaps understandable given the complexity of the service system and the difficulty this introduces into the examination of service outcomes, it comes at a high cost. In a recent report of health care expenditures of children with special health care needs (SHCN), an estimated 16.2 percent of children with SHCN accounted for 41 percent of total health care expenditures of children (Chevarley, 2006). Similarly, children with disabilities currently comprise 15 percent of all Medicaid recipients, yet account for 37 percent of all costs (Ronder, Kastner, Parker, & Walsh, 1999). Children with ASD, specifically, are estimated to have significant health care expenditures (Liptak et al., 2006), and may incur lifetime costs as high as $12 million (Jarbrink & Knapp, 2001). A lack of information hinders the development of standards of care for a group of children who are relatively high users of public and private funded behavioral and medical health services (Liptak et al., 2006; Ruble, Heflinger, Renfrew, & Saunders, 2005; Thomas et al., 2006).

1.1. What are the views from consumers of services?

Certainly the best approach to begin to understand the helpfulness of a treatment is to utilize a formal experimental design. However, there are few controlled studies examining any of the treatments commonly used for those with ASD, there are even fewer studies comparing alternate treatments, and there are no studies that examine the combination effect of multiple treatments for ASD (Kasari, 2002). When experimental data are not available, views of stakeholders concerning a treatment can be helpful (e.g., parents, caregivers, persons with ASD). However, currently there are very few studies available on stakeholder perspectives on outcomes of services in autism (Thomas, Morrissey, & McLaurin, in press). The few studies available have focused on general satisfaction (e.g., would you recommend this treatment provider; were you satisfied with the treatment; what services are important to you) (e.g., Bromley, Hare, Davison, & Emerson, 2004; Kohler, 1999; Liptak et al., 2006), rather than ratings of actual treatment improvement (e.g., based on the treatment your son or daughter received, rate his/her improvement on each of the following symptoms). Kohler (1999) interviewed 25 families in Western Pennsylvania who had a child between 3 and 9 years with ASD. Parents were asked to report concerns with the service system. The most frequently endorsed issue by 64 percent of families was that at least one existing service or provider was deemed ineffective in meeting the child's or family's needs. Examples were that the treatment methods did not produce the desired outcomes or the providers did not address skills valued by the parents.

Bromley et al. (2004) examined the issue of service satisfaction in more detail. They analyzed relationships between service satisfaction, other types of services received, and characteristics of the family and child. In their sample of 68 mothers from the United Kingdom, parents were more likely to report satisfaction with school services when they received formal and informal supports as well as other specialized services for their child such as placement in a special rather than mainstream school. They found no relationships between satisfaction with school services and gender, age or ethnicity of the child, household composition or income, or severity of the child. They did, however, discover patterns between the child's developmental level and number of services received. Children who were reported as being more self-absorbed and as having more severe developmental delays in language, independence, and socialization accessed a higher number of different support services as well as a higher number of services perceived as ‘‘appropriate’’ in the previous 6 months. They also found a significant relationship between number of services used and age of the children; younger children used more services.

As noted earlier, although helpful, these studies are of limited use in providing estimates of effectiveness because of their focus on caregiver satisfaction with services. In contrast, parental ratings of the outcomes of services for specific symptoms are more relevant in assessing potential differences in effectiveness and in helping to guide public policy and planning. The purpose of the current study was to provide direct information from parents and caregivers on the outcomes of community-based services. The study also examined utilization of formal service supports and caregiver ratings of family and child service outcomes. Four specific questions were examined: (1) caregiver ratings of the outcomes of services, (2) service characteristics predictive of caregiver perception of outcomes (e.g., service intensity), (3) child and family characteristics predictive of caregiver perception of outcomes, and (4) the effects of polytherapy, specifically the reception of conjoint pharmacological and psychosocial therapy, on caregiver perception of outcomes.

2. Methods

2.1. Survey development and distribution

The survey was originally developed at the request of, and in collaboration with, the State Interagency Council for Services to Children with an Emotional Disability (SIAAC), the Autism Spectrum Disorder Advisory Consortium (ASDAC), and the Kentucky Department of Mental Health and Mental Retardation Services (DMHMRS). These state agencies had a common goal of seeking needed information for policy planners, program administrators, service providers, advocates, parents and caregivers, and researchers to begin to understand the parental perceptions of service outcomes and to have a documented basis for making improvements (see Ruble & Gallagher, 2004 for the full report). The study was approved by the University of Louisville Institutional Review Board.

To attempt to obtain widespread community representation, three sources of survey distribution were used. The DMHMRS mailed surveys to public service agencies. Parents and advocates who were members of ASDAC distributed surveys to parent groups of the Autism Society of America as well as other parent support groups. A parent member of ASDAC also developed a web-based version of the survey that was sent via Internet to autism related listservs

Table 1
Types of services and outcomes surveyed

Services evaluated
Inpatient hospitalization
Medication
Family counseling/training
Individual therapy
In-home behavior therapy
Speech and language therapy
Occupational therapy
Case management
Respite care
Outcomes evaluated
Improvement in child at home
Improvement in child at school
Improvement in child's behavior
Improvement in child's communication
Improvement in child's social skills
Improvement in child's problem solving
Less stress on caregiver
Less stress on family overall
Less financial worry

in Kentucky. Because of the various methods of distribution used, it was not possible to determine the response rates. The representativeness of the respondents, however, was evaluated and included in the analysis.

The primary purpose of the survey was to obtain information on utilization and effectiveness of frequently used services for persons with ASD. Information on family demographics and personal and clinical characteristics of the children with ASD also were obtained to see how these variables related to services. Questions were generated based on similar surveys previously conducted in Indiana, Tennessee, and Kentucky. Initial questions were reviewed by, and modified based on feedback from the stakeholder groups. The final survey consisted of 43 questions that included demographic and background information as well as questions concerning utilization and outcomes of nine types of services (see Table 1). A copy of the survey is available from the primary author. The demographic questions were used to help subdivide the sample in further understanding the results, and included five child variables (age, gender, race, diagnosis, and classroom placement, which was used as a proxy indicator of severity of autism) and five family variables (marital status, income, education, number of children, and type of insurance—public or private funded) (see Tables 2 and 3). The nine types of services surveyed (e.g., respite care, medication management) were selected to be representative of the array of services provided by schools and financed by public and private insurance providers in Kentucky (see Table 1). Nine possible outcomes, or service effectiveness ratings, were assessed for each type of service. The outcomes focused on child factors (6 ratings) and family factors (3 ratings). The child-focused outcome ratings included four targeting improvement in specific psychosocial outcomes assessing core features of autism (i.e., behavior problems, difficulties in communication, social skills, problem solving) and two targeting overall improvement in the two settings where children spend most of their time (i.e., home and school). Family-focused outcome ratings targeted three domains commonly affected by having a child with autism (i.e., family stress, caregiver stress and financial worry—see Table 1). Respondents used a Likert scale (1 "strongly disagree" to 5

Table 2
Respondent characteristics compared to Kentucky census

	Respondent characteristics, *N* (percent)	Kentucky census, *N* (percent)
Education		
Graduate/professionals	28 (24.8)	182,051 (6.9)
College graduate	40 (35.4)	400,899 (15.2)
Some college	21 (18.6)	490,170 (18.5)
High school graduate	22 (19.5)	888,277 (33.6)
Some high school	1 (.9)	375,707 (14.2)
Junior high	1 (.9)	309,293 (11.7)
Marital status		
Never married	5 (4.4)	
Spouse is parent of child with ASD	82 (72.6)	
Spouse not parent of child with ASD	8 (7.1)	
Widowed	1 (.9)	
Divorced	14 (12.4)	353,637 (11)
Separated	2 (1.8)	57,237 (1.8)
Income		
<10,000	7 (6.2)	220,692 (13.9)
10,000–24,999	14 (12.4)	379,011 (23.8)
25,000–49,999	32 (28.3)	481,628 (30.2)
50,000–100,000	38 (33.6)	396,538 (24.9)
100,000+	107 (15)	113,870 (7.2)
Number of children	$M = 2$ (*SD*: .88), range 1–5	
Type of insurance		
Employer-funded	85 (77)	2,297,120 (56.5)
Public-funded	24 (22)	634,249 (15.6)

Note: Type of insurance based on information from http://www.kff.org/mfs/medicaid.jsp?r1=KY&r2=US.

"strongly agree") to rate the outcomes of the services they had received during the past 6 months (e.g., "As a direct result of this service my child is doing better at home.").

In addition to the nine individual outcome ratings, an overall family outcome and an overall child outcome were created for each service, by summing the individual scores within each service. Finally, the average effectiveness across all services was calculated by summing the within service overall child and family outcomes score, and dividing by the number of services utilized.

2.2. Participant characteristics

A total of 113 caregivers responded to the survey. Respondents were from 46 different counties distributed broadly across the Commonwealth of Kentucky. Eight-nine percent of respondents were mothers, 7 percent were fathers, 2 percent were grandparents, and 2 percent were adoptive parents. Marital status was generally comparable to the Kentucky census; however, education and income were somewhat higher and representation from African Americans was low (see Table 2).

The average age of the children with ASD was 9.9 years (see Table 3). The average age at diagnosis was about 3.7 years, however, treatment began on average when the children were

Table 3
Characteristics of the children with ASD

Characteristic	*N* (percent)
Gender	
Males	98 (87)
Females	14 (12.5)
Race	
Caucasian	106 (93.8)
African American	1 (.9)
Multicultural	4 (3.5)
Native American	1 (.9)
Age	*M* = 9.9 years (*SD*: 4.4), range 2.5–21.0 years
Age range	
<2	2
3–5	15
6–11	56
12–21	37
Age diagnosed	*M* = 3.7 years (*SD*: 2.7), range 1–16 years
Diagnosis	
Autism	87 (77)
Asperger's	14 (14)
PDD-NOS	10 (9)
Rett's	1 (1)
Age TX started	*M* = 3.3 years (*SD*: 2.9), range 0–18 years
Type of classroom attended most of day	
Regular	40 (35.4)
Resource	25 (22.1)
Self-contained	30 (25.7)

3.3 years. Eighty-six percent of the children were in public schools, 6 percent in private school, 6 percent home-schooled, and 1 percent in a vocational program. Of those in public school, about 35 percent attended a regular education program and the rest were in full day special education or resource room programs. Caregivers reported that 77 percent of the children had an autism diagnosis; 14 percent were diagnosed with Asperger's Disorder and 9 percent with Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS).

3. Results

3.1. Outcomes of services based on caregiver perception

Caregivers reported that the mean number of services used in the past 6 months was 3.5; a finding consistent with previous research (Goin-Kochel et al., in press; Kohler, 1999; Thomas et al., 2006). Caregiver ratings of service effectiveness differed depending on whether child or family outcomes were examined (see Table 4). For child outcomes, when overall effectiveness was rated, in-home behavior therapy was rated as the most effective and medication as the second most effective service for both the home and school settings. When improvement in individual child outcome domains was examined, in-home behavior therapy was again rated as the most effective intervention for two domains (communication and behavior), and as the second most

Table 4
Mean effectiveness ratings of type of service by family and child outcomes[a]

Service	Mean (*SD*)										
	Child outcomes (the services resulted in improvement at or in. . .)							Family outcomes (the service resulted in less. . .)			
	Home	School	Behavior	Communication	Social skills	Problem solving	Overall	Family stress	Caregiver stress	Financial worry	Overall
In-home behavior therapy (*N* = 25)	4.4 (.95)	4.4 (1.0)	4.4 (.95)	4.3 (.97)	4.2 (1.1)	4.0 (1.1)	4.3 (.93)	4.0 (1.1)	4.1 (1.1)	3.1 (1.8)	3.8 (1.07)
Medication management (*N* = 71)	4.2 (.70)	4.1 (.74)	4.0 (.76)	3.4 (1.0)	3.2 (.97)	3.2 (1.1)	3.7 (.75)	3.4 (1.2)	3.5 (1.2)	2.3 (1.1)	3.1 (.96)
Parent counseling/training (*N* = 41)	4.0 (.82)	3.8 (.99)	3.8 (.93)	3.8 (.98)	3.6 (1.0)	3.2 (1.1)	3.7 (.80)	3.7 (1.1)	3.6 (1.0)	2.6 (1.4)	3.3 (.90)
Individual therapy (*N* = 47)	4.0 (.99)	3.9 1.0()	3.7 (1.0)	3.7 (1.1)	3.6 (1.1)	3.5 (1.2)	3.7 (.94)	3.3 (1.2)	3.4 (1.2)	2.9 (1.4)	3.3 (1.11)
Respite care (*N* = 33)	3.8 (1.1)	3.6 (.97)	3.8 (1.1)	3.5 (.94)	3.7 (.96)	3.4 (1.0)	3.6 (.92)	4.4 (.90)	4.4 (.88)	3.7 (1.3)	4.2 (.88)
Speech/language therapy (*N* = 86)	3.6 (1.0)	3.7 (.96)	3.3 (1.1)	3.7 (1.0)	3.6 (1.1)	3.3 (1.1)	3.5 (.94)	3.1 (1.3)	3.1 (1.3)	2.9 (1.4)	3.0 (1.19)
Occupational therapy (*N* = 77)	3.6 (1.1)	3.6 (1.1)	3.3 (1.1)	3.2 (1.1)	3.3 (1.1)	3.3 (1.0)	3.4 (.97)	3.2 (1.2)	3.2 (1.2)	2.9 (1.3)	3.1 (1.12)
Case management (*N* = 30)	3.4 (1.2)	3.4 (1.3)	3.2 (1.1)	3.0 (1.2)	3.0 (1.3)	2.9 (1.2)	3.2 (1.19)	3.2 (1.3)	3.3 (1.3)	3.1 (1.5)	3.2 (1.28)
Inpatient/residential (*N* = 7)	3.3 (1.6)	2.8 (1.3)	3.0 (1.3)	2.9 (1.3)	3.1 (1.3)	2.8 (1.5)	3.0 (1.35)	2.8 (1.9)	2.4 (1.6)	2.1 (1.7)	2.5 (1.55)

[a] Based on Likert scale (1 “strongly disagree” to 5 “strongly agree”).

effective for a third (out of four)—social skills. Medication was rated as the most effective intervention in one child outcome domain (social skills) and as the second most effective for two others (behavior and problem solving). For the fourth child outcome area, problem solving, occupational therapy was rated as the most effective intervention.

For family outcomes, respite care was ranked consistently as the most effective service in reducing caregiver, family, and financial stress. Similar to the findings for the child outcomes, in-home behavior therapy was highly rated; it was ranked as the second most effective intervention in helping with family stress. However, in contrast to the child outcomes, medication was not rated as one of the top interventions for any of the family outcomes.

3.2. Service characteristics predictive of outcomes

We were interested in whether outcomes were related to the types or frequency of services received. Pearson product–moment correlation was used to examine the relationship between mean across-services ratings of family and child outcomes and the number of different types of services received and the overall frequency of those services. The correlation between the frequency of all services received during the past 6 months (i.e., total number of visits or units of service of all types of services received, such as speech therapy, medication management, etc.) and the mean across-services child ($r = .16$, *ns*) and family outcomes failed to reach significance ($r = .18$, *ns*). In contrast, there was a significant association between the number of different types of services used (i.e., families received from one to nine different types of services) and ratings of mean family ($r = .65$, $p < .001$), but not child ($r = .18$, *ns*) outcomes.

The relationship between frequency of service utilization and outcomes was next explored separately within each of the nine service categories (see Table 5). Overall service utilization for each individual intervention was correlated with the within-category mean overall child and family outcome scores. Child outcomes were unrelated to frequency of use for all nine services. However, frequency of use was significantly correlated with mean overall family outcome for two services. Caregivers reported better overall family outcome when their children received more frequent individual therapy ($r = .303$, $p < .05$) and more frequent in-home behavior therapy ($r = .460$, $p < .05$). In summary, although frequency of services did not affect overall child outcomes, there appears to be a dosage effect of service utilization on overall family outcomes.

Table 5
Means, standard deviations, and correlations of frequency of services received with child and family outcomes

Frequency of service received	*M*	*SD*	Child outcomes	Family outcomes
Inpatient hospitalization	53.8	67.7	.066	−.080
Medication management	3.0	2.3	.094	.147
Parent counseling/training	7.7	8.2	.187	.307
Individual therapy	56.6	56.5	−.019	.303*
In-home behavior therapy	74.1	57.1	−.082	.460*
Speech/language therapy	42.7	30.9	−.050	−.174
Occupational therapy	28.9	24.9	.218	.045
Case management	9.0	7.0	−.222	−.360
Respite care	10.3	11.1	.246	.044

* $p < .05$.

Table 6
Impact of family and child factors on family and child outcomes

	Family outcomes	Child outcomes
Family factors		
Marital status	$F(5, 90) = 1.16$, *ns*	$F(5, 87) = .95$, *ns*
Number of children	$r = .10$, *ns*	$r = -.05$, *ns*
Level of education	$F(5, 90) = 1.28$, *ns*	$F(5, 87) = .88$, *ns*
Level of income	$F(4, 87) = 1.14$, *ns*	$F(4, 84) = .795$, *ns*
Type of insurance	$F(2, 90) = .194$, *ns*	$F(2, 87) = 1.29$, *ns*
Child factors		
Race of child	$F(3, 91) = .13$, *ns*	$F(3, 88) = .12$, *ns*
Age	$r = -.26$, $p < .01$	$r = -.15$, *ns*
Gender	$F(1, 93) = .04$, *ns*	$F(1, 91) = 1.79$, *ns*
Classroom placement	$F(3, 82) = .75$, *ns*	$F(3, 79) = .37$, *ns*
Diagnosis	$F(2, 90) = 0$, *ns*	$F(2, 87) = .17$, *ns*
Medication	$F(1, 94) = 1.50$, *ns*	$F(1, 91) = .20$, *ns*

3.3. Child and family characteristics predictive of outcomes

Analyses were conducted to begin to understand the potential impact of family demographic (see Table 2, e.g., number of children, level of education), child demographic (see Table 3, e.g., child race, age, gender) and child clinical/severity factors (e.g., use of medication, diagnosis, type of classroom attended most of day) on the mean child and family outcomes averaged across all service categories. One-way analysis of variance was used for categorical independent variables (e.g., child gender) and Pearson product–moment correlation was used for continuous variables (e.g., child age). With respect to the five family demographic variables, none of the analyses indicated a relationship with the child or family mean overall outcome scores (see Table 6). With respect to the child variables, only one factor, age of the child, was significantly related to outcomes. Age correlated significantly with overall outcomes for the family, but not the child. Caregivers and parents with younger children reported better overall outcomes for the family ($r = -.264, p < .01$).

3.4. Synergistic effect of pharmacological and psychosocial interventions on outcome

The foregoing analyses were limited to examining the effects of interventions in isolation. We also were interested in examining the effects of polytherapy, specifically the possible potentiating effect of medications in enhancing the perceived effectiveness of non-pharmacological interventions. To explore the interactive relationship, a two-way between group analysis of variance was conducted to explore the joint impact on child and family outcomes of receiving one of the specific psychosocial interventions and taking medications. The dependent variables used were the mean within-category child outcome scores and the mean within-category family outcome scores. The key test of the hypothesis was the interaction effect. Table 7 displays the mean caregiver-rated child outcomes based on whether or not the child was receiving medication and whether or not the child received the particular service. There were no statistically significant main or interaction effects for any intervention. However, two services, in-home behavior therapy and case management revealed a nearly significant interaction effect ($p = .083$ and $p = .072$), respectively. When family outcomes were examined, no significant interaction effects or trends toward significance were revealed.

Table 7
Joint effect of receiving medication and individual services on child outcomes

Service	Received medications				ANOVA *F*		
	Yes		No		Service (S)	Medication (M)	S × M
	M (*N*)	*SD*	*M* (*N*)	*SD*			
Inpatient					2.12	.02	–
Yes	22.9 (7)	5.4	–	–			
No	19.6 (55)	5.0	19.5 (34)	5.6			
Parent counseling/training					1.79	.11	.07
Yes	20.7 (25)	4.4	20.6 (13)	3.4			
No	19.4 (37)	5.6	18.8 (21)	6.6			
Individual therapy					.52	.24	.75
Yes	20.9 (29)	4.9	19.4 (17)	5.2			
No	19.1 (33)	5.2	19.6 (17)	6.1			
In-home behavior therapy					.03	1.71	3.1
Yes	21.6 (14)	3.3	17.5 (8)	7.9			
No	19.5 (48)	5.5	20.1 (26)	4.7			
Speech and language therapy					2.66	1.39	1.19
Yes	20.1 (49)	4.6	20.0 (30)	4.9			
No	19.3 (13)	7.1	15.5 (4)	9.4			
Occupational therapy					.01	.64	.73
Yes	19.7 (46)	4.8	19.8 (25)	4.5			
No	20.7 (16)	5.9	18.9 (9)	8.2			
Case management					.19	1.28	3.3
Yes	21.9 (22)	3.8	18.1 (8)	7.2			
No	19.0 (40)	5.4	19.9 (26)	5.1			
Respite care					1.43	.135	.00
Yes	21.0 (21)	3.7	20.5 (10)	5.0			
No	19.5 (41)	5.7	19.0 (24)	5.9			

4. Discussion

What little is known currently about intervention outcomes for children with autism spectrum disorders (ASDs) comes largely from treatment efficacy studies. Overall these studies demonstrate that the number of hours and duration, type, and intensity of intervention received by children with ASDs are associated with developmental outcomes (Dawson & Osterling, 1997; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999). However, information on the probable effectiveness of many types of services as commonly delivered both in the clinic and in the community is simply lacking (i.e., effectiveness) (Bryson, Rogers, & Fombonne, 2003; Goin-Kochel et al., in press; Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001). Consequently, the gap between real world services outcomes and treatment study outcomes (Bodfish, 2004; Ruble et al., 2005) is becoming increasingly untenable. In an era in which evidence based practices (e.g., services that have been shown to be effective in two or more randomized controlled trials) are becoming the standard of care in both the medical and psychosocial arenas, there is virtually no evidence that the current array of services commonly delivered for those with autism are even helpful, much less that they could meet these more rigorous standards. Moreover, as noted earlier, this gap in the empirical evidence includes not only experimental research, but also correlational and survey research that can help inform hypotheses and provide preliminary data on outcomes. Accordingly, the current study sought to begin to provide some initial data on effectiveness, by asking caregivers to report on the outcomes of services received.

The findings from the study provide new information on both the types of services used for children with ASD and their perceived helpfulness. Outcomes for nine different types of commonly applied interventions were examined. Outcomes for the child were evaluated in terms of setting (home vs. school) and effect on symptoms of autism (social, communication, behavior, and problem solving). In-home behavior therapy was rated as having the best outcomes for the child across both the home and school settings, and also displayed the most consistent pattern of positive outcomes across individual symptom domains. Medication ranked a close second to in-home behavior therapy in reported effectiveness for the child at home and school and across outcome domains. In contrast, when the impact of services on outcomes for the family was examined, respite care was identified as the most effective service.

This pattern of findings is consistent with the intended target of the interventions, those aimed at helping the child were rated as most effective for the child (e.g., medication), and those aimed at helping the family were rated as most effective for the family (i.e., respite). Moreover, caregivers' rated preferences for in-home behavior treatment and medications are consistent with formal effectiveness research, which indicates that both medications and behavioral treatments can be effective for children with autism (Alessandri, Thorp, Mundy, & Tuchman, 2005; Posey & McDougle, 2001; Tanguay, 2000). To date, the literature has failed to provide similar experimental data supporting the effectiveness of the other services we examined. That parents also seem to indicate the superiority of these two services provides both some validation for the previous experimental results and serves to enhance confidence in the obtained parent ratings.

There was some evidence for a dosage effect on treatment outcomes. Higher service intensity was associated with better overall family, but not child outcomes, for those receiving individual and in-home behavior therapy. That is, for these services, the higher the frequency of service, the higher the rated effectiveness. Family outcomes also were significantly better when families reported using a variety of different types of services, although outcomes were unrelated to the frequency of total services received. That is, individual service frequency and total number of types of services received both impacted caregiver reported family outcomes. In contrast, neither the total number of different services nor the types of services used had any impact on child outcomes. This latter finding is contrary to Bromley and colleagues' (2004) findings that parents whose children received more services reported greater satisfaction with services overall. However, satisfaction with services is not necessarily the same as ratings of outcome effectiveness. Moreover, it is possible that family stress (family outcomes) may be alleviated by increased services, e.g., due to increased attention and support of professionals, even when changes in the child's behavior are small or negligible (see Bromley et al., 2004).

Analysis of the relationship of the parent/caregiver and child demographic variables to child and family outcomes revealed only one significant finding. Consistent with previous research, a child's age was a predictor of service satisfaction (Bromley et al., 2004). Younger children were reported to have better family outcomes. This finding suggests a need for providers to better understand the needs of older individuals and their parents or caregivers in an effort to provide more effective or meaningful services. That parents of younger children should be more satisfied is particularly surprising given the very high importance placed on early intervention and the relative lack of funding resources and trained, available providers to support such interventions. However, many of these children entered treatment before receiving an ASD diagnosis, suggesting that these families may have been especially proactive in seeking early help for their children. Alternatively, parents of older children may become less satisfied over time, reflecting a sense of burnout and loss of optimism concerning the degree of progress and future prognosis of their children.

As noted in the introduction, a possible reason for the dearth of information on effectiveness is that no single agency is responsible for the variety of services needed by, and provided for, children with ASD. The current findings confirmed that services are not delivered in isolation. Polytherapy tends to be the rule and not the exception. Caregivers reported that the mean number of services used was 3.5, which is generally consistent with other reports (Goin-Kochel et al., in press; Kohler, 1999; Thomas et al., 2006). Despite the fact that use of polytherapy is typical, studies rarely examine the possible benefits (e.g., synergistic effects) or costs (e.g., treatment interference or side effects) of providing two or more services simultaneously. For example, an often stated benefit of medication management is that it can potentiate other therapies by reducing the behavior problems or anxiety sufficiently to allow the child to benefit from the non-medication therapy. Indeed, in the current sample, pharmacological therapy was the third most common form of treatment, in almost all cases it was provided along with other therapies, and, as noted earlier, it was generally perceived as helpful. Unfortunately, when tested, pharmacological treatment did not show a potentiating effect in enhancing the outcomes of non-pharmacological interventions such as speech therapy. However, the analyses were underpowered and there was a trend ($p < .10$) for both in-home behavior therapy and case management to produce better results in combination with medications. Despite these generally positive findings concerning medications, it should be noted that there also is the potential for the misuse of medications in those with developmental disabilities generally, and with autism specifically. For example, individuals have raised concerns about the efficacy of medications used to treat autism, variability in response to those medications, and potentially serious side effects from those medications (Tuchman, 2004). Thus, caution is needed in interpreting these initial results. Clearly further research will be needed to more definitively explore the synergistic effects of medication as part of polytherapy in those with autism.

4.1. Limitations of the study

The study had several limitations. The sample size, although relatively large for studies of autism, was limited to a small subset of the individuals who were solicited. It is unclear how participants may have differed from those who did not participate. Although there were indications that the sample resembled the rest of the state in marital status and race, there were significant differences based on education and income. It is likely that individuals with less education or income might have different needs from the current sample. Another limitation was that the effective samples for comparisons were nested within service type. That is, not every family received every service. Thus, because the samples of individuals receiving different services were not necessarily equivalent, differences in satisfaction with specific services could also represent sampling differences. However, given that services are individualized and vary naturally, this limitation may be difficult to surmount in field research.

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References

Alessandri, M., Thorp, D., Mundy, P., & Tuchman, R. F. (2005). Can we cure autism? From outcome to intervention. *Revue Neurologique, 40*(Suppl. 1), S131–S136.

Bodfish, J. W. (2004). Treating the core features of autism: Are we there yet? *Mental Retardation and Developmental Disabilities Research Review, 10*, 318–326.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*, 409–423.

Bryson, S. E., Rogers, S. J., & Fombonne, E. (2003). Autism spectrum disorders: Early detection, intervention, education, and psychopharmacological management. *Canadian Journal of Psychiatry, 48*, 506–516.

Chevarley, F. (2006). *Utilization and expenditures for children with special health care needs*. *Research findings* (Vol. 24). Rockville, MD: Agency for Healthcare Research and Quality.

Dawson, G., & Osterling, J. (1997). *The effectiveness of early intervention*. Baltimore: PH Brookes.

Goin-Kochel, R. P., Myers, B. J., & Mackintosh, V. H. (in press). Parental reports on the use of treatments and therapies for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*.

Hoagwood, K., Burns, B. J., Kiser, L., Ringeisen, H., & Schoenwald, S. K. (2001). Evidence-based practice in child and adolescent mental health services. *Psychiatric Services, 52*, 1179–1189.

Hurth, J., Shaw, E., Izeman, S.-G., Whaley, K., & Rogers, S.-J. (1999). Areas of agreement about effective practices among programs serving young children with autism spectrum disorders. *Infants and Young Children, 12*, 17–26.

Jarbrink, K., & Knapp, M. (2001). The economic impact of autism in Britain. *Autism, 5*(1), 7–22.

Kasari, C. (2002). Assessing change in early intervention programs for children with autism. *Journal of Autism and Developmental Disorders, 32*, 447–461.

Kohler, F. W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities, 14*, 150–158.

Liptak, G., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders, 36*, 871–879.

Posey, D. J., & McDougle, C. J. (2001). Pharmacotherapeutic management of autism. *Expert Opinion on Pharmacotherapy, 2*, 587–600.

Ronder, R. W., Kastner, T., Parker, S. J., & Walsh, K. (1999). Serving people with developmental disabilities in Medicaid managed care. *Managed Care Quarterly, 7*, 23–30.

Ruble, L., & Gallagher, T. 2004. *Parental and caregiver experiences with services, utilization, and costs in Kentucky: A preliminary analysis for autism spectrum disorders*. Retrieved January 3, 2007, from University of Louisville, Systematic Treatment of Autism and Related Disorders. Web site: http://www.starautism.louisville.edu/images/pdf/summary%20reportfinal.pdf.

Ruble, L. A., Heflinger, C. A., Renfrew, J. W., & Saunders, R. C. (2005). Access and service use by children with autism spectrum disorders in Medicaid Managed Care. *Journal of Autism and Developmental Disorders, 35*, 3–13.

Tanguay, P. E. (2000). Pervasive developmental disorders: A 10-year review. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 1079–1095.

Thomas, K., Ellis, A., McLaurin, C., Daniels, A., & Morrissey, J. (2006, May). *Family use of effective elements of programs for autism*. Poster session presented at the annual meeting of the International Meeting for Autism Research, Montreal,Canada.

Thomas, K., Morrissey, J., & McLaurin, C. (in press). Use of autism-related services by families and children. *Journal of Autism and Developmental Disorders*.

Tuchman, R. (2004). AEDS and psychotropic drugs in children with autism and epilepsy. *Mental Retardation and Developmental Disabilities Research Reviews, 10*, 135–138.