

University of Kansas
School of Social Welfare

**SERVICE CHALLENGES FOR
CHILDREN WITH AUTISM
SPECTRUM DISORDERS AND
MENTAL HEALTH NEEDS**

Office of Child Welfare and Children's Mental Health

Prepared by:

Stephanie Bryson, LISW, Susan K. Corrigan, Ph.D. & Cheryl Holmes, MPA

**This effort was supported through a contract with the Kansas Department of Social
and Rehabilitation Services, Division of Health Care Policy**

ACKNOWLEDGEMENTS

The authors wish to thank and acknowledge the gracious assistance of: School of Social Welfare staff Kris Matthews, Terry Moore, Sharah Davis, Peggy Taylor, Sarah Potter, and Emily McCave; Linda Brown; all professionals from CMHCs and CDDOs who participated in surveys and interviews; Colin McKinney of COMCARE, Wendy Lockwood of the Center for Counseling and Consultation, and Nathan Fawson of Southeast Kansas Mental Health for hosting focus groups; Pattie Noonan, Matt Enyart, Kaye Otten, and Rich Simpson; parents and staff of Families Together and the Autism Society of America—especially Kirsten and David Sneid for their essential help in recruiting focus group participants; Sue Ann Kline, Jenny Layton, and the University of Kansas Autism Asperger Resource Center; The Governor’s Commission on Autism; and last but certainly not least, all the parents who shared with us their poignant, resilient, and frustrating experiences.

EXECUTIVE SUMMARY

Study Purpose

In FY 2006, through a contract with the Kansas Department of Social and Rehabilitative Services, Health Care Policy division, the University of Kansas School of Social Welfare undertook a study of service provision to children with autism spectrum disorders (ASDs). The purpose of the study was to clarify the nature of service delivery to families of children with coexisting mental health needs and an ASD diagnosis; to evaluate the current and future collaboration between the community mental health centers (CMHCs) and the community developmental disability organizations (CDDOs); and to assess the need for innovative funding streams to facilitate the delivery of timely, appropriate services.

Methods

The present study was designed to describe the Kansas population of children with autism spectrum disorders, to chart service utilization in the mental health system, and to understand provider and parent perspectives regarding adequacy of service delivery. Following are primary data sources for the study:

- Literature review of etiology, incidence, prevalence, and service delivery
- Review of best practices in screening, diagnosis, and intervention
- Review of autism-specific state funding strategies
- Descriptive analysis of service utilization from the Automated Information Management System (AIMS) database
- Online survey of Kansas CDDO directors and CMHC Community Based Services directors
- Four regional focus groups with parents of children with ASD diagnoses
- Ten phone interviews with parents of children who were unable to attend focus groups
- Key stakeholder interviews and additional data sources

Key Findings

Research Question #1: What characterizes the population of children and youth with an autism spectrum disorder? How are they served in Kansas CMHCs?

- **In 2004, Kansas CMHCs served approximately 15% of the children estimated to have an autism spectrum disorder.**
 - This service rate may underestimate the actual number of children served in CMHCs because at least nine CMHCs enter primary diagnosis only in mental health center database, the Automated Information Management System (AIMS). Furthermore, not all children with an autism spectrum disorder would be expected to have co-occurring mental health needs.

- **Kansas children with autism spectrum disorders share similar demographic and diagnostic features with the national population: They are 4:1 boys to girls, carry attention deficit/hyperactivity and disruptive behavior disorder diagnoses, and present with significant impairments in functioning.**
- **The great majority of children with autism or another ASD, at the time of the study, lived at home with their families, remained out of hospitals and in school, and did well academically. Children with autism fared somewhat better in this regard than their counterparts with other ASDs, who were more likely to encounter out-of-home placements, school problems, inpatient hospitalizations, and JJA involvement.**
- **It is likely that CMHC services provided significant stability for this population at high risk for hospitalization and other poor outcomes.**

Research Question #2: How does treatment differ in CMHC and CDDO systems? What are the main service barriers encountered by each system? What collaborative service options exist?

- **CMHCs exclusively provide all therapeutic services, including medication management. CDDOs exclusively provide supportive home care and family support stipends. Both systems provide case management, attendant care, respite, social skills groups, and behavioral support. Service availability varies considerably across the state.**
- **According to CBS and CDDO directors, the biggest impediment to delivering timely, appropriate services is the current funding level of the developmental disability (DD) system.**
- **Related barriers to services in both systems include: 1) long waiting lists and a dearth of competent local providers; 2) among both CMHC and CDDO staff: a lack of training, expertise, knowledge of best practices, or desire to work with this population; and 3) a noteworthy lack of coordination between systems—primarily CDDOs and CMHCs, but also schools.**
- **Directors from both systems expressed a desire for greater coordination across systems and recognized the deleterious effects of its absence.**

[We need]...improved coordination between CDDOs and CMHCs. Sometimes children with these disorders fall through the cracks. Some PDDs, like autism, do not qualify a child as SED in the mental health system, which may limit services that can be accessed. (CMHC director)

- **To mitigate these barriers, directors suggested: 1) increasing funding to the DD system; 2) clarifying the roles of each agency with regard to children with ASDs, perhaps through program and policy guidelines; 3) creating specific ASD waivers to serve all children and youth, 0-22, or at the very least, the 0-5 population; 4) providing local, joint training with other systems and providers; and 5) creating regional diagnostic centers.**

Research Question #3: Which services appear to fit consumers' unique needs? What system appears best suited to meet consumers' needs?

- **No one system is best suited to serve all consumers' needs. Both systems are needed to serve the diverse needs of this population, on a case-by-case basis pending determination of eligibility.**
- **Three factors make the establishment of general service guidelines difficult: 1) the idiopathic nature of autism spectrum disorders; 2) the expansion of both ends of the spectrum to include high functioning children with autism (and no comorbid cognitive deficits) and lower functioning children with other ASDs (and some cognitive deficits); and 3) the idiosyncratic nature of co-occurring psychiatric disorders in children with ASDs.**
 - For example, parents expressed frustration with the limitations of both systems. Most parents of children with *autism* were able to receive services only through the CDDO, with the exception of medication management, which they accessed through the CMHCs. However, they sometimes faced up to a three-year wait for DD services. Parents of children with severe autism and self-harming behaviors felt keenly abandoned when they were placed on DD waiting lists and refused services through the mental health system. On the other end of the spectrum, parents of children with high functioning autism and no mental retardation were turned away from CDDOs because their children's IQs were too high.
 - Parents of children with an *ASD diagnosis other than autism* were more likely to access services through the CMHCs. However, parents in our sample had little overall contact with CMHCs and were more likely to have accessed services through hospitals or private providers.
- **By self-report, neither CMHCs nor CDDOs alone are prepared to meet the unique needs of this population.**
- **In the absence of adequate funding, CDDO directors feel ill prepared to serve children with ASDs. Some directors believe that CMHCs should also serve children with cognitive limitations.**

- Similarly, CMHCs feel overwhelmed by their mandate to serve this population regardless of HCBS availability. Many CBS directors remarked that children with ASDs and their families required the funding and services CDDOs could provide, so that mental health centers did not become the providers of only resort. Two director quotes, below, illustrate these points:

Expand expertise of mental health professionals to use treatment methodologies/best practices with children with cognitive limitations, or provide an adequate funding stream for the DD system to provide clinical treatment services, since the DD system has the expertise (CDDO director).

Eliminate the waitlist for MR/DD waiver. Mental health cannot do it all for these kids, and we need the services that this waiver would provide (CBS director).

Research Question #4: What barriers do parents face in 1) identifying the need for services, 2) obtaining services, and 3) financing services?

Identifying the need for services:

- **Parents expressed frustration with the diagnostic process. Many encountered long waits (6 months to 13 years); were disappointed when Infant and Toddler Services (ITS) and other early intervention programs failed to send them to a specialist sooner; struggled to get their pediatricians to give a diagnosis; and felt hindered by bureaucratic and school delays in procuring requisite functional evaluations and appropriate special education services.**
- **Parents from all regions of the state had the best experiences with the few specialty providers in the Kansas City area: The University of Kansas Medical Center, the Autism Asperger Resource Center, Children’s Mercy Hospital, and a small number of private providers. Many parents sought out-of-state consultations.**

Obtaining Services

- **Overall, parents in our sample had more experience with the CDDOs and were more satisfied with CDDOs than with CMHCs. This was true even of parents who were on the waiting list for the MR/DD waiver.**
- **Parents who qualified for the SED waiver were the exception; they were far more likely to express satisfaction with their CMHC experiences.**

- Some parents expressed a great deal of gratitude for waiver services. However, some parents on both waivers complained that determinations were slow in coming and did not provide enough financial support or service flexibility for their children’s needs.
- As mentioned above, parents of children with *autism* were frustrated by the lack of services for which they qualified in both CDDOs and CMHCs. Moreover, some parents of *children with dual diagnoses* received little from their CMHCs and eventually got services from hospitals and private practitioners. Several cited waiting lists for appointments in CMHCs. For example:

Community Mental Health, their family focus is well intended. *I think they have one behaviorist. That’s the piece about crisis. If you’re going to have a crisis, call and make an appointment. You know, it’s sad, but again this all will come down to funding.* (NE Region)

Another parent described the experience of a close friend who has not been able to get appointments at the CMHC during crises:

They cannot get another appointment when they’re having major problems with their child. *Oppositional behavior, you know...I guess they’re going to have to wait until he does something truly heinous, or violent...* (NE Region)

One parent described an acute lack of services from either system in a western part of the state in which the CDDO provides no direct services to children:

And the tragic thing is you feel like you’ve lost all these years *because what good would it have done over the last three years if we would have had the services that we needed and the help that we needed. We could have probably maintained her at home. We would have probably been, if we could have had attendant care, somebody to watch her and help us at home, but those services weren’t available. So she went to the hospital.* (Western Region)

Financing services:

- **The financial burden of autism spectrum disorders is significant for parents of all incomes.** If children are not eligible for waivers, or if insurance will not cover developmental disorders, the expense of treatments can be very costly.
- **Some single parents reported that they quit their jobs in order to home school their children who were receiving few services from the schools.**

- Middle and upper income parents in our sample paid out of pocket to procure diagnoses, behavioral consultations, trainings for themselves, or other services.
- Some parents receiving Medicaid conveyed frustration that the options mentioned above—procuring trainings or consultation—were closed to them. They could not pursue alternative treatments in the same manner as parents with higher incomes and had to rely on the expertise of those providers willing to accept Medicaid reimbursement.
- Two parents in the study sample relinquished custody of their child to SRS in order to get needed residential services.
- Many spouses quit their jobs to take care of their child with an ASD; one mother has been her child’s full-time paraprofessional at school for the last six years.

The whole way we have bought and paid for consultants with Visa cards and any means that we could get. We are on the waiver. That’s \$150 a month that we get to help out with all this. Visa cards, that’s our real waiver. (Western Region)

So I called my case manager at Infant and Toddler Services and said, “It’s come to my attention that perhaps he should go to KU.” Because my husband and I are like, “Well, what do we do? What do we do?” And so she said, “Well, maybe you could do that. Is your insurance company going to cover it?” And I said, “I don’t know. Well, how much is it?” She goes, “Well, it’s like \$1500.” Now, of course here we are now, three years later we’ve spent almost \$60,000, but at the time, “What? \$1500?” (NE Region)

Research Questions #5 & 6: What are other states doing to meet consumers’ needs? What innovative ideas or best/promising practices exist? What are some national options bridging the funding gap?

Four states currently have autism-specific waivers: Wisconsin, Colorado, Indiana, and Maryland. Massachusetts is in the process of passing an autism waiver. Waivers differ widely in eligibility requirements and coverage. The most inclusive waiver is Wisconsin’s, which covers all children and youth, aged 0-22, with any autism spectrum disorder. Other states have expanded services to this population by use of TEFRA/Katie Beckett waivers. These options hold promise for the Kansas ASD population because waiting lists for MR/DD services could be reduced. Further cost & feasibility analyses are needed.

Policy Implications/Considerations for Next Steps

1. **Consider passage of an early childhood autism waiver.** At the least, an early childhood waiver could mitigate delays in diagnosis and treatment, which compound the severity of disability and the cost of services over the child's life span.
2. **Consider passage of a comprehensive autism waiver.** A comprehensive autism waiver for individuals aged 0-22, with an additional Katie Beckett option for parents with higher incomes, could greatly expand services to children who need them and potentially save the state Medicaid monies.
3. **Support the creation of regional diagnostic centers** and/or telemedicine initiatives.
4. **Increase workforce capacity in CMHCs, CDDOs, and schools by training staff in currently accepted best practices. Establish an infrastructure of ongoing supervision and consultation.** Specialty providers in Kansas City may be utilized for trainings and supervision.
5. **Create a specialized division within SRS, like Massachusetts' Autism Division.**
6. **Establish an interagency coordinating committee** made up of SRS-HCP staff, CMHCs, CDDOs, and schools.
7. **Develop service protocols delineating primary agency responsibility in the case of dual diagnosis.** Diagnostic algorithms, however, are not recommended.
8. **Draft state-wide service provider list for parents of children just diagnosed.**
9. **Work with Kansas Insurance Department to assess fidelity to Kansas Mental Health Parity Act.** Assess whether insurance denials cost the state more in Medicaid funds.
10. **Improve rural service availability** by offering incentives for specialty providers, by re-assessing service coverage of administrative-only CDDOs, and by fostering regional collaboratives to address service gaps in the western and southeastern regions of the state.
11. **Increase pool of specialists** by offering incentives to resident and non-resident psychiatrists and medical professionals willing to remain in state and specialize in neurodevelopmental disorders.

12. **Change data recording procedures** for CMHCs so they record all ASD diagnoses—primary or secondary. This will permit a more accurate estimate of the ASD population served by Kansas CMHCs.
13. **Allow funding discretion** for parents so they can fund what they most need, with accountability measures built in.
14. **Study more optimal service delivery models to children with ASDs and mental health needs.** Year two of this initial, descriptive study will analyze waiver utilization patterns and recommend strategies for optimizing service delivery.

TABLE OF CONTENTS

1. Background.....	1
1.1.1 Report outline.....	2
2. Methodology.....	3
2.1.1 Research questions.....	3
2.1.2 Data sources.....	3
2.1.3 Limitations of the study.....	6
2.1.4 Stakeholder feedback.....	6
3. National Picture.....	8
3.1.1 Review of literature.....	8
3.1.2 Defining “autism spectrum” disorders.....	8
3.1.3 Autistic disorder.....	9
3.1.4 Rett’s disorder.....	9
3.1.5 Childhood disintegrative disorder.....	9
3.1.6 Asperger’s disorder.....	9
3.1.7 PDD not otherwise specified.....	10
3.2.0 Etiology of autism spectrum disorders.....	10
3.3.0 Controversies over the incidence and prevalence of ASDs.....	10
3.3.1 Importance to states of population estimates.....	12
3.4.0 Best current estimates of prevalence.....	13
3.4.1 Autism spectrum disorders.....	13
3.4.2 Prevalence of mental retardation in individuals with autism.....	13
3.4.3 Prevalence of psychiatric comorbidity.....	13
3.4.4 Demographic factors, race, and gender.....	14
3.5.0 Empirically supported practices.....	14
3.5.1 Early identification, assessment, and diagnosis.....	14
3.5.2 Cost benefits of providing early, intensive behavioral intervention.....	15
3.6.0 Service challenges for children with ASDs.....	15
3.6.1 Factors associated with age at diagnosis.....	16
3.6.2 Access and service use.....	16
3.6.3 Medical expenditures.....	17
3.6.4 Dual diagnoses.....	17
4. Overview of current autism spectrum disorder waiver programs.....	19
4.1.1 Autism waivers.....	19
4.1.0 Wisconsin.....	19
4.2.0 Indiana.....	20
4.3.0 Colorado.....	20
4.4.0 Maryland.....	20
4.5.0 TEFRA/Katie Beckett option.....	21
5. Kansas findings: AIMS data analysis.....	22
5.1.1 Limitations of data sources.....	22
5.2.0 Children with autism served by Kansas CMHCs.....	24
5.2.1 Acuity.....	30
5.2.2 SSDI eligibility.....	30
5.2.3 Calendar year of service start.....	30
5.2.4 Population density.....	30

TABLE OF CONTENTS, CONTINUED

5.2.5 Reason for stopping waiver31

5.2.6 Length of service.....31

5.2.7 Reason for discharge.....31

5.3.0 Child population description.....33

5.4.0 Comorbid psychiatric diagnoses37

5.4.1 Children with secondary autism diagnoses.....37

5.4.2 Children with secondary ASD diagnosis38

5.4.3 Discharge information for children w/ secondary autism or ASD dx39

5.5.0 Functional levels of children diagnosed with autism or other ASD40

5.5.1 Prior hospitalization40

5.5.2 Chronicity at end of time period40

5.7.0 Conclusion: AIMS data analysis.....45

6. Kansas findings: CBS and CDDO director survey46

6.1.0 Purpose.....46

6.2.0 Respondents and services provided46

6.2.1 Specific interventions.....48

6.3.0 Most common co-occurring diagnoses49

6.4.0 Subjective assessment of agency preparedness with ASDs.....51

6.5.0 Service challenges.....54

6.6.0 Provider recommendations58

6.6.1 Community mental health center responses58

6.6.2 Community developmental disability organization responses59

6.7.0 Conclusion: provider survey61

7. Kansas findings: Parent focus groups and interviews.....62

7.1.1 Themes from parent focus groups, interviews, and questionnaires62

7.1.2 Most helpful services, general62

7.1.3 Identifying the need for services.....64

7.1.4 Obtaining services.....66

7.1.5 Financing services.....70

7.2.0 Parent recommendations71

8. Policy implications/recommendations74

9. References79

APPENDICES, TABLES, & FIGURES

Tables

Table 1: Summary of Current Autism Waiver Criteria	21
Table 2: Unduplicated Children with Autism Served by Kansas CMHCs: Number and Rate per 1,000	24
Table 3: Unduplicated Children with Asperger’s Syndrome, PDD-NOS, or Rett’s Syndrome Served by Kansas CMHCs: Number and Rate per 1,000.....	26
Table 4: Service Demographics	28
Table 5: Service Demographics, Continued	29
Table 6: General Demographics	33
Table 7: Educational Information	34
Table 8: Child Welfare Status.....	35
Table 9: Primary Diagnoses of Children Secondarily Diagnosed with Autism	37
Table 10: Primary Diagnoses of Children Secondarily Diagnosed with 299.8	38
Table 11: Child Functioning	40
Table 12: Functional Levels.....	43
Table 13: Services Provided by CMHCs and CDDOs	46
Table 14: Specific Interventions Used in CMHCs and CDDOs.....	48
Table 15: Reported Common Comorbid Diagnoses.....	50
Table 16: CMHC and CDDO Combined Perception of Agency Preparedness.....	53
Table 17a: CBS & CDDO Director Responses to Biggest Service Delivery Question.....	56
Table 17b: CBS & CDDO Director Responses to Biggest Service Delivery Question	57

Figures

Figure 1: Percentage of Estimated Autism Population Served by Kansas CMHCs	25
Figure 2: Percentage of Total ASD Population Served by Kansas CMHCs in 2004	27
Figure 3: SPMI/SED among Children with Autism	41
Figure 4: SPMI/SED among Children with ASDs	41
Figure 5: Chronicity at End of 2004	42
Figure 6: Breakdown of Agency Services as Reported by Survey Respondents	47
Figure 7: Specific Interventions and their Frequency in CMHCs and CDDOs.....	49
Figure 8: CMHC & CDDO Report of Commonly Diagnosed Psychiatric Disorders	50
Figure 9: CMHC Respondent Rating of Preparedness	51
Figure 10: CDDO Respondent Rating of Preparedness.....	52

Appendices

Appendix A: Sample Focus Group Flyer.....	86
Appendix B: Consent Form, Parent Focus Groups.....	87
Appendix C: Parent Focus Group Questions	90
Appendix D: Parent Focus Group Questionnaire	91
Appendix E: Provider Survey Consent Form	94
Appendix F: Selected Provider Survey Responses	97
Appendix G: List of Best Practice Recommendations	99
Appendix H: Guidelines for Differential Diagnosis of Dually Diagnosed Children.....	104

SERVICE CHALLENGES FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS AND MENTAL HEALTH NEEDS

1. BACKGROUND

Like many states, Kansas struggles to serve children and youth who are dually diagnosed with an autism spectrum disorder (ASD) and mental health needs. In most communities, services to children with the most prevalent spectrum disorders—autism, Asperger’s disorder, and pervasive developmental disorder not otherwise specified (PDD NOS)—are delivered through at least two distinct systems: the developmental disability system and the community mental health system. Access to services may vary significantly across the agencies and private contractors that comprise these separate administrative structures. Where services are available, public and private financing are frequently inadequate to meet the service needs of this low incidence, high acuity population. Funding is a particular challenge for children with significant disability who do not qualify for assistance through either of the HCBS waiver mechanisms designed to prevent institutionalization: the Persons with Developmental Disabilities (MR/DD) Waiver and the children with Severe Emotional Disturbance (SED) Waiver.

In 2004, the University of Kansas School of Social Welfare (KU) conducted a study of the children’s mental health provider network, “Assessing the Need For Change in the Kansas Public Mental Health System.” This study produced a notable finding. Parents in focus groups expressed concern about an apparent lack of coordination between the community developmental disability system and the community mental health system. Parents reported that neither community developmental disability organizations (CDDOs) nor community mental health centers (CMHCs) “adequately embraced” the complex and costly needs of their children dually diagnosed with a developmental disability and co-occurring mental health needs. Children with dual diagnoses may require a range of costly services, including evaluation by a neurodevelopment specialist; neurological and neuropsychological examinations; genetic testing; audiologic testing; social and cognitive interventions; case management; special education; speech and physical therapies; respite; and psychiatric evaluation, psychotherapy, and medication monitoring.

In response to parent feedback, Kansas Social and Rehabilitative Services, division of Health Care Policy (SRS-HCP) contracted with the University of Kansas School of Social Welfare (KU) to conduct a study of service delivery to children with an ASD and co-occurring mental health needs. The purpose of this project was 1) to clarify the nature of service delivery to families of children who have both an ASD and co-occurring mental health needs; 2) to evaluate the potential for collaboration between the CMHCs and CDDOs; and 3) to assess the need for innovative funding streams to facilitate the delivery of timely, appropriate services.

1.1 Report Outline

This report includes background information on service delivery to children with an autism spectrum disorder and other psychiatric diagnoses and discusses noteworthy financing innovations from other states. Using service data from a 2004 extract of the mental health center database, the Kansas population of children with ASDs and mental health needs is described. Results from a survey of CDDO and CMHC directors are presented. Finally, parent focus group findings and policy implications are discussed.

Note: In the following report, children with autism were analyzed separately from children with other autism spectrum disorders, including Rett's disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. Information about children with autism is presented first throughout the report, followed by information about children with other autism spectrum disorders. This presentation is not intended to prioritize one group over the other; it was simply written this way for ease of communication.

2. METHODOLOGY

2.1.1 Research Questions

This project was guided by the following questions:

- 1) What characterizes the population of children and youth with an autism spectrum disorder. How are they served in Kansas CMHCs?
- 2) How does treatment differ in CMHC and CDDO systems? What are the main service barriers encountered by each system? What collaborative service options exist?
- 3) Which services appear to fit consumers' unique needs? What system appears best suited to meet consumers' needs?
- 4) What barriers do parents face in 1) identifying the need for services, 2) obtaining services, and 3) financing services?
- 5) What are other states doing to meet consumers' needs? What innovative ideas or best/promising practices exist?
- 6) What are some national options for bridging the funding gap?

2.1.2 Data Sources

National Data

1. Literature Review
Clinical and service delivery literatures were reviewed. The purpose of the literature review was to document the state of knowledge regarding etiology, symptomatology, empirically-based intervention, and effective service delivery to this low incidence, high acuity population.
2. Review of State Funding Strategies
This review identified current Medicaid service delivery strategies. Autism-specific waivers are now in place in four states: Wisconsin, Colorado, Indiana, and Maryland. A summary of the waivers is provided, as well as a brief discussion of the TEFRA/Katie Beckett Option.

Kansas Specific Data

1. Demographic and Service Statistics
To gain a sense of service delivery patterns, an extraction of data from the Community Mental Health Centers' Automated Information Management System (AIMS) was obtained. Using data from calendar year 2004, youth were selected who had a DSM-IV-TR (2000) diagnosis of autistic disorder (299.0); childhood disintegrative disorder (299.1); or pervasive developmental disorder NOS, Rett's disorder, or Asperger's disorder (299.8). Youth were selected who had any of these diagnoses as the primary diagnosis during treatment, the secondary diagnosis during treatment, the primary diagnosis at discharge, or the secondary diagnosis at discharge. The number of children with a diagnosis of childhood disintegrative disorder (299.1) was predictably quite small. It was therefore not analyzed independently. For the children who had more than one admission

during this time period (e.g., child served at one CMHC, moved and received services at another CMHC), data from the most recent admission were used.

Additionally, to provide a clearer picture of comorbid psychiatric disorders and the process by which clinicians arrive at a final diagnosis of ASD, we separated children with primary vs. secondary diagnoses of autism or another ASD and looked at diagnosis at intake and at discharge for these two groups.

2. CDDO and CMHC Provider Survey

In October 2005, Community Based Services (CBS) directors convened a meeting. At this meeting, the study's Principal Investigator requested that directors assist KU in carrying out a survey of service delivery experiences with the population in question. Directors expressed a desire to complete an email survey rather than an in-person survey. Additionally, the study's principal investigator and project coordinator met with Margaret Zillinger, Director of Community Supports and Services for the state of Kansas to ascertain the desirability of conducting such a survey with CDDO directors. It was determined that this would be a viable means of obtaining data from CDDOs. Accordingly, an electronic survey was created using an online survey website (see Appendix F). Margaret Zillinger and Mike Hammond, Executive Director of the Association of Community Mental Health Centers of Kansas, sent letters of support to 28 CDDO and 28 CBS directors, respectively, encouraging them to complete the online survey. Forty-seven respondents completed the survey—22 from Community Mental Health Centers and 25 from Community Developmental Disability Organizations. Response rate was 84%. Responses represented 19 CMHCs and 19 CDDOs. Questions covered a range of topics— from directors' subjective perceptions of service adequacy to specific types of interventions used in individual agencies. In addition to likert scale and multiple choice questions, respondents were given the opportunity to write in narrative comments at different points in the survey. These comments were coded and analyzed qualitatively.

3. Parent Focus Groups and Phone Interviews

Between February and April 2006, KU staff conducted four focus groups with parents of children with an ASD and mental health needs. The goal of the focus groups was to gain a better understanding of parent experiences obtaining and financing services. Participants were asked to complete a two-page questionnaire, followed by a 1 to 1 ½ hour focus group. A total of 19 parents and one regional CDDO provider participated in the focus groups and 17 questionnaires were completed. (Two married couples participated and filled out only one questionnaire.) Focus groups were both digitally recorded and audiotaped; sessions were then transcribed and analyzed qualitatively.

Several interested parents were unable to attend a planned focus group. To accommodate these parents, KU staff conducted phone interviews with any parent who met criteria for the study and who requested an interview. Ten parents from

across the state were interviewed by phone. Phone interviews were audiotaped. In addition, staff took detailed notes. Tapes and notes were analyzed qualitatively.

Questionnaires, focus groups, and phone interviews elicited information about parents' capacities to obtain an accurate diagnosis; to obtain needed services from public and private venues (with an emphasis on Medicaid-reimbursed services); and to finance these services privately, through Medicaid, or through MR/DD or SED waivers. Researchers utilized the following recruitment strategies:

- Four regions of the state were chosen: northeast, southeast, south central, and west. Focus group fliers (Appendix A) were sent to CBS and CDDO directors in agencies located in the four regions. Researchers asked directors to help recruit parents of children with an ASD, particularly those who had sought services through CMHC or CDDO systems and preferably those whose sole means of financing services was Medicaid. If necessary, researchers spoke directly with CBS and CDDO directors to troubleshoot recruitment obstacles.
- KU staff spoke, corresponded, or met with key stakeholders in the Autism community, including all Kansas chapters of the Autism Society of America and Families Together. Organizers of the Johnson County Autism Society and several regional coordinators of Families Together were particularly responsive to requests for help organizing focus group participants. Participants were recruited through word of mouth and online through an Autism Society website. Additionally, stakeholders sometimes facilitated phone interviews with parents who were unable to attend scheduled focus groups.

Ultimately, focus groups were conducted in the northeast, south central, and western regions of the state. The southeast region focus group was cancelled due to lack of attendance. However, researchers conducted phone interviews with parents from this region. In all, KU staff interviewed 29 parents of children with autism spectrum disorders.

4. Key Informant and Expert Interviews

Throughout the duration of the project, KU staff members met with service providers, advocates, and other key informants. Some of these organizations and individuals included: CDDO liaisons; faculty of the KU Department of Special Education; parent advocates; members of the Governor's Commission on Autism; specialist providers at Children's Mercy Hospital; and specialist providers at KU's Autism and Asperger Resource Center. Additionally, staff attended a presentation by a leading national expert from Yale University's Child Study Center Developmental Disabilities Clinic, Ami Klin. The presentation focused on empirically-based treatments for autism spectrum disorders

2.1.3 Limitations of the Study

This study was intended to provide an overview of the population of children with autism spectrum disorders and existing challenges to serving them. Due to an anticipated wait for MMIS data, researchers chose to utilize the AIMS database for this year of the study. Sole use of the AIMS database limited our ability to compare MR/DD and SED waiver usage or CDDO versus CMHC service types or intensities. Moreover using one year of cross-sectional data restricted our capacity to track, in a meaningful way, changes in CBCL scores, or to understand the conditions under which children ended treatment.

Although we sought carefully to estimate the population of children we might expect the community mental health centers to serve, our ability to do so was limited by three things: 1) lack of statistical certainty in epidemiological literature about the prevalence of autism in the general population; 2) lack of certainty in psychiatric literature about the prevalence of other psychiatric disorders within the autism population; and 3) possible underreporting by CMHCs that enter only primary diagnoses in the AIMS database.

Subsequent study will allow for an analysis of service delivery using linked Medicaid, CMHC, and DD system databases. As adequate data will exist in the next fiscal year, subsequent study can also make use of longitudinal design to better capture data about changes in a child's condition over time. These data, in turn, can inform policy and programming decisions.

2.1.4 Stakeholder Feedback

Researchers sent a draft copy of the final report to representatives of the following stakeholder organizations: Autism Society of America, Families Together, Kansas Coalition for Autism Legislation, and the Autism Asperger Resource Center. Additionally, individual stakeholders with expertise in autism received copies of the report. Stakeholders submitted feedback through phone conversations or emails with the study's Project Coordinator. The following summarizes stakeholder feedback:

- In general, stakeholders responded positively to the content of the report and felt it was an accurate reflection of their constituencies' experiences.
- The Kansas Coalition for Autism Legislation requested that researchers review additional studies regarding the science substantiating the claim that thimerisol-containing vaccines have caused an increase in the incidence of autism. Researchers reviewed this additional information and modified this section of the report accordingly.
- The Autism Society of America offered the following suggestions:
 - Use state extension programs to train autism providers— including teachers, speech language pathologists, occupational therapists, physicians, masters level social workers, psychologists, and registered nurses. These providers could then provide services to families in the communities nearest them.

- Use of extension programs could open up funding streams within universities and colleges and increase the financial base for autism research.
- Community colleges could offer a degree for behavioral aides (through a certification program). Graduates of this program would create a pool of trained providers that area school districts, community mental health centers, and CDDOs could utilize. This would decrease the cost to agencies of training small groups and would offer a more uniform and quality controlled training program. It would also offer graduates a chance at a livable wage with insurance benefits. Moreover, graduates might be able to stay in the community in which they receive their degree.
- Encourage medical schools to allow medical students to have dual specialties, e.g. pediatricians could minor in neurodevelopmental disorders.
- Mitigate shortage of developmental pediatricians by training community care developmental pediatric nurses. Nurses could provide thorough developmental screenings and thus ameliorate long waits for diagnosis and services.
- Create multi-use “compassionate campuses” for older individuals with autism spectrum disorders. These could be modeled on the Southwest Autism Research and Resource Center (SARRC) in Phoenix, AZ. SARRC has created a blueprint for a safe community living/working/playing campus. Their website is www.autismcenter.org.

NATIONAL PICTURE

3.1.1 Review of Literature

The review of literature begins with a general overview of autism spectrum disorders. Current controversies surrounding incidence and prevalence are then considered and a best estimate of national prevalence provided. Treatment and services literatures are reviewed, and finally, information is presented about autism-specific Medicaid waivers and the Katie Beckett/TEFRA Medicaid option.

3.1.2 Defining “Autism Spectrum” Disorders

Originally described by psychiatrist Leo Kanner in 1943, autism did not appear as a discrete diagnostic entity until publication of the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1980. DSM-III defined the disorder as a condition marked by *lack of responsiveness to other human beings, gross impairments in communication and language, and bizarre responses to the environment*. For the first time, DSM-III also grouped autism with several other disorders whose functional limitations “pervaded” every aspect of a child’s life. “Pervasive developmental disorder,” or PDD, is the term still used in the DSM, although the particular syndromes under this umbrella have undergone multiple revisions. The DSM-IV-TR (2000) includes the following disorders in the PDD category: autistic disorder, Rett’s disorder, childhood disintegrative disorder (CDD), Asperger’s disorder (AD), and PDD not otherwise specified (PDD NOS).

In the past ten years, the term “autism spectrum disorders”(ASD) has gained favor among clinicians and researchers. As reflected in statements from the Centers for Disease Control (CDC), the National Institute of Mental Health (NIMH), and the Johns Hopkins University Center for Autism and Developmental Disabilities Epidemiology (CADDE), ASD is the currently preferred term because it underscores commonalities shared by these disorders while recognizing that they exist on a spectrum of acuity. According to Johns Hopkins researchers, “We prefer ASD over PDD because it emphasizes the common ‘autism-like’ features of all of these specific diagnoses and, at the same time reflects the wide variation in the manner and severity that individuals are affected” (Autism Fact Sheet, CADDE).

To confuse matters somewhat, ASD has another popular usage. It can also designate a subset of the most commonly diagnosed disorders—autism, Asperger’s disorder, and PDD NOS—which are thought to exist on a spectrum of severity from autism to Asperger’s disorder. In this second usage, Rett’s disorder and childhood disintegrative disorder are excluded from the autism spectrum on the basis that they are comparatively rare, have a clearer genetic etiology (Rett’s), and have poorer prognoses than other ASDs (California Department of Developmental Services, 2002).

Note: In this report, ASD refers to all five disorders as they appear in the current DSM. However, due to the low prevalence of Rett’s and CDD and to methodological limitations imposed by their categorization in the DSM, we cannot provide reliable statistical information on the true prevalence of each

specific disorder. This matter is discussed further in the Findings section of the report. Brief descriptions of each diagnostic category follow.

3.1.3 Autistic Disorder

Autistic disorder, or autism, is a neurodevelopmental disorder characterized by impairments in verbal and/or nonverbal communication; social interaction; and repetitive, unusual, or circumscribed behaviors. While autism may encompass a broader range of functionality than previously thought, and while children may present quite differently, Tidmarsh and Volkmar (2003) provide a heuristic illustration of a child with autism:

A typical example is a 3-year-old child who does not speak and does not respond when parents call his or her name. Such children seem to be in their own world when left alone; in day care, they tend to isolate themselves from the group. They do not play with toys but, instead, perhaps repetitively stack blocks or push a toy car back and forth while lying on the floor. They are sensitive to loud noises and cover their ears when trucks pass by. They flap their hands and turn their bodies in circles. (p. 518).

Autism prevalence will be discussed in a subsequent section of the literature review.

3.1.4 Rett's Disorder

This is a rare disorder (1/20,000) with a clear genetic etiology (in most cases). Rett's disorder occurs almost exclusively in girls. It is marked by head circumference deceleration between 5 and 48 months, followed by loss of previously acquired fine motor skills, the onset of hand wringing, the eventual loss of motor function, and significant lack of coordination in trunk and gait movement. Affected girls lose communication skills and interest in their environment. At this stage, Rett's symptoms appear similar to symptoms of autism. However, between two and ten years of age, some girls regain the ability to make eye contact and to interact socially, surpassing the social aptitude of many children with autism. Rett's disorder is associated with severe, or profound, mental retardation.

3.1.5 Childhood Disintegrative Disorder (CDD)

Rarer than Rett's disorder, childhood disintegrative disorder has a prevalence rate of only 1.7/100,000. It affects males more than females and is marked by loss of previously acquired skills after a period of normal development. To meet DSM criteria, a child must demonstrate marked deterioration in two of the following areas of development: social skills or adaptive behavior, language, bowel or bladder control, play, or motor skills. CDD appears to have a poorer outcome than autism (Volkmar, 1997).

3.1.6 Asperger's Disorder (AD)

Asperger's disorder is usually detected at a later developmental stage than autism. Language development may appear normal or even precocious at three years old. However, children with Asperger's disorder eventually display problems communicating with others because their speech is often one-sided, oblivious to cues of social reciprocity, and preoccupied with specific circumscribed interests (like washing

machines, time, or the solar system). According to Tidmarsh and Volkmar (2003), children with AD “may make inappropriate statements in public or, sounding like little professors, use unusual and sophisticated words. Their prosody is affected, and they may speak in a boring monotone” (p. 519). Children with AD may have normal cognitive ability, but they often have learning disabilities. In school, they may have difficulty attending to anything but their circumscribed interests. Academic achievements in this population are not uncommon; however, children and adults with AD suffer from isolation, stigma, depression and anxiety because of problems interacting socially. Prevalence of Asperger’s disorder will be discussed in the next section of the literature review.

3.1.7 PDD-Not Otherwise Specified

PDD NOS is a category used when clinicians cannot satisfy full criteria for other categories. Children with less severe presentations of any other ASD may be given a PDD NOS diagnosis. Despite, or perhaps because of its clinical imprecision, PDD NOS is now the most widely used ASD diagnosis (Fombonne, 2003). Some researchers feel that the category contributes little to our understanding of ASDs and creates too many false positives, “with ramifications not only for research but also for service providers and schools” (Volkmar, 2003, p. 519). Prevalence of PDD NOS will be discussed shortly.

3.2.0 Etiology of Autism Spectrum Disorders

The etiology of autism and ASDs is unknown. Research continues in the areas of genetics, neurology, and metabolic disorders. A genetic component is increasingly accepted among scientists, with family heritability demonstrated. At present, it appears that there may be multiple neurological and developmental pathways to ASDs (Perry & Condillac, 2003).

3.3.0 Controversies over the Incidence and Prevalence of ASDs

There is little consensus in the scientific community—and considerable controversy in the media—about the incidence and prevalence of autism and autism spectrum disorders. What is clear is that the *prevalence* rate of autism and ASDs has increased in the past ten years; there simply *are* now more children with ASDs than in the 1960s, when the accepted prevalence rate was 4/10,000. What remains controversial is the *cause* of the increased prevalence.

High prevalence rates from recent studies have sparked an incendiary debate in the media and among public policy makers. Do the higher numbers mean that we now have an epidemic of autism? Many in the scientific community—including the most established autism researchers—maintain that higher prevalence rates are due to changes in diagnostic criteria and to improved awareness of symptoms among diagnosing professionals (Tidmarsh & Volkmar, 2003). Epidemiologists (Fombonne, 2003; Costello, Foley, & Angold, 2006) also point to significant variability in the design of large studies over the years, which confounds accurate predictions of trends in ASD prevalence over time. Fombonne notes, “Surveys conducted in the 1960s and 1970s only dealt with autism (as opposed to ASD) and with a rather narrow definition of autism, as per

Kanner’s description, and not accounting for autism occurring in subjects who are not mentally retarded” (2003, p. 87).

A true epidemic of autism would point to an actual increase in incidence—that is, in the number of new cases occurring. An increase in incidence, in turn, would point to an environmental “exposure.” In recent years, advocacy and parent groups have demanded that the government conduct research into a putative link between mercury found in thimerosal, a preservative used in some children’s vaccines until 1999, and the onset of a “regressive” type of autism in which apparently normally developing children experience a sudden loss of skills shortly after receiving a routine vaccination. The measles-mumps-rubella immunization has also been a suspect in search for the cause of ASDs.

To date, there exists no clear confirmatory evidence of environmental exposures leading to increased incidence of ASDs. A conclusive causal association between ASDs and the measles-mumps-rubella immunization has not been found in recent epidemiological studies (Fombonne & Chakrabarti, 2001; Madsen, Hviid, & Vestergaard, 2003; Taylor, Miller, Lingam, et al., 2002). To date, evidence that mercury-containing vaccines are causal in the incidence of ASDs is also inconclusive (Stratton, Gable, & McCormick, 2001; Pichichero, Cernichiari, Lopreiato, & Treanor, 2002). Despite the lack of scientific “proof” that mercury-containing vaccines cause autism, some scientists (Haley, 2005; Geier & Geier, 2003) have suggested that children with autism are unable to metabolize mercury and that they continue to receive doses of methylmercury from vaccines in excess of government safety guidelines. Moreover, the epidemiological studies upon which current wisdom is based may be insufficiently sensitive to detect a link, for example, between the MMR vaccine and autism in children with a genetic predisposition for it. Although it did not support a correlation between vaccine and autism, the Institute of Medicine (IOM) in its 2004 report could not conclusively rule out “the possibility that vaccines contribute to autism in some small subset [of the population]” (Kirby, 2005, 360). Iowa and California have passed legislation banning thimerisol from pediatric vaccines; 32 other states are considering doing so.

To summarize, researchers agree that the number of children diagnosed with autism spectrum disorders has increased dramatically since the 1960’s. *Prevalence* has thus increased. Researchers attribute this, in large part, to changes in diagnostic criteria and to increased awareness among professionals giving ASD diagnoses. Researchers do not agree that increased prevalence is due to an actual increase in *incidence*—that is, the number of newly emerging cases. To prove increased incidence, researchers would have to demonstrate a causal connection between an environmental agent—like mercury in vaccines— and autism. At present, such evidence is inconclusive. But while an epidemic of autism has not yet been wholly scientifically substantiated, it cannot be completely ruled out either. As epidemiologist Eric Fombonne states, “Whereas evidence exists that a substantial part of the increase in prevalence is due to methodological factors, the additional possibility of a secular increase in the incidence of autism cannot be ruled out” (2003, p. 88).

3.3.1 *The Importance to States of Population Estimates*

Accurate estimates of this population are increasingly important to policy makers and public service agencies. Federal legislation mandates that two programs serve children with disabilities: The Individuals with Disabilities Education Improvement Act of 2004 (IDEA, Public Law 108-446; U.S. Department of Education, 2004) and Medicaid (Title XIX of the Social Security Act). IDEA requires two things: that schools provide a free and appropriate public education to children with disabilities, including autism, and that an accurate number of eligible children be counted. Between 2000 and 2001, the United States Department of Education (US DOE) reported a 21% increase in the number of children between the ages of 6 and 21 years who had autism (US DOE, 2001). In 1999, the Department of Education called autism the “largest growing low incidence disability in the U.S.” (US DOE, 1999). Moreover, the California Department of Health and Human Services (Department of Developmental Services, 1999) reported that between 1987 and 1998, the number of children seeking services for autism rose by 273%.

Some prominent researchers (Shattuck, 2006; Fombonne, 2003) have criticized these numbers, citing the phenomenon of “diagnostic substitution.” In order to draw down early intervention funding, an incentive may exist to re-classify some children’s diagnoses so they will qualify for services. For example, in the widely publicized University of California MIND Institute study (2002), the prevalence of autism increased from 5.8 per 10,000 children in 1987 to 14.9 per 10,000 in 1994. Upon reanalysis of the data, however, it appeared that the prevalence of mental retardation during this period decreased concomitantly—from 28.8 to 19.5 per 10,000. The best explanation for this sudden decline in mental retardation was the substitution of autism for mental retardation in order to qualify children for early intervention services (Croen, Grether, Hoogstrate, & Selvin in Fombonne, 2003).

While the cause of the increase remains unclear, “the mounting numbers of children seeking services is clear and inarguable” (Ruble, Heflinger, Renfrew & Saunders, 2005, p. 3). The ramifications of this trend are particularly important for state Medicaid programs. At present, Medicaid is the largest single public payer of behavioral health services (Mark, Buck, Dilonardo, Coffey, & Chalk, 2003) and a key resource for people with developmental disabilities. In 2000, Medicaid funding for developmental disabilities accounted for 75% of all DD services. Furthermore, in 1992, 31% of children with disabilities were covered primarily by Medicaid, compared to 18% of children without disabilities (Mele & Flowers, 2000). While children with disabilities comprise just 15% of all Medicaid recipients, they account for 37% of total costs (Ronder, Kastner, Parker, & Walsh, 1999). Some have expressed concern that in order to control costs, states are unintentionally underserving the population of children with disabilities, including ASDs (Ruble, et al., 2005). However, given the high costs associated with severe disability, and the preponderance of evidence that early and intense intervention can change the course of autism spectrum disorders, states would be unwise to do so (Jacobson & Mulick, 2000).

3.4.0 Best Current Estimates of Prevalence

3.4.1 Autism Spectrum Disorders

In the interest of providing SRS-HCP with an accurate estimate of the population of children with ASDs, multiple epidemiological sources were reviewed and evaluated.

Recently, the Centers for Disease Control conducted two large population-based studies in two U.S. cities (Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle, & Murphy, 2003; Bertrand, Mars, Doyle, Bove, Yeargin-Allsopp, & Decoufle, 2001). The studies reported an ASD prevalence of 34 and 67 per 10,000 children, respectively. Bearing in mind the methodological limitations of each survey, leading autism epidemiologist Eric Fombonne states:

Increasing and consistent evidence from recent surveys show that the prevalence rate for ASDs (including not only autism disorder but also Asperger disorder and pervasive developmental disorder-not otherwise specified) is approximately **60 per 10,000**" (2003, p. 87).

Translated, this estimate means that at present, there are approximately 425,000 children under 18 in the United States with an autism spectrum disorder. Of those, 114,000 children are under five years old. Very recently, the CDC conducted two nationally representative surveys—the National Health Interview Survey (NHIS) and the National Survey of Children’s Health Survey (NSCH). The prevalence of autism and other ASDs reported by parents was very close to the rate identified in prior surveys: “5.7 per 1,000 children in NHIS and 5.5 per 1,000 children in NSCH” (CDC, 2006).

To compute estimated prevalence of children with **autism spectrum disorders** in Kansas, this report will use the currently accepted rate of **60 in 10,000, or 6 in 1,000** children. The report will use the more conservative CDC rate of **5.5 per 1,000** to estimate the prevalence of **autism only**.

3.4.2 Prevalence of Mental Retardation¹ in Individuals with Autism

Fombonne (2003) reports that autism is associated with mental retardation in about 70% of cases and is more than four times more likely to occur in males than in females. The ratio is currently 4.3:1 (p. 379).

3.4.3 Prevalence of Psychiatric Comorbidity

No reliable statistics exist with regard to the prevalence of commonly co-occurring psychiatric disorders in the population of children with ASDs. Common disorders include: anxiety, depression, oppositional behavior, hyperactivity, poor attention, tic disorders, and compulsive behavior. Of these disorders, depression and anxiety are

¹ Intellectual disability, mental retardation, and cognitive disability are used interchangeably in this report. While the authors recognize that “intellectual or cognitive disabilities” are currently preferred terms, we wish to remain faithful to what was actually measured in the research we are reporting. Thus, studies which use the category “mental retardation” will be reported accordingly.

thought to be most common among persons with autism and other ASDs (Ghaziuddin, Ghaziuddin, & Greden, 2002; Tidmarsh & Volkmar, 2003). While it has long been known that high functioning individuals with ASDs experience symptoms of depression and anxiety, recent research also points to high rates of depressive symptoms among those with severe intellectual disabilities—children (Bradley, Summers, Wood, & Bryson, 2004) and adults (Ghaziuddin, Ghaziuddin, & Greden, 2002).

Children with ASDs are commonly diagnosed with attention deficit/hyperactivity disorder (ADHD). For some time, researchers have reported spurious diagnoses of ADHD in children with ASDs (Jensen, Larrieu, Mack, 1997; Clark, Feehan, Tinline, Vostanis, 1999). However, some clinical researchers (Yoshida & Uchiyama, 2004) believe that ADHD should be assessed in children with ASDs, despite the DSM-IV exclusion of inattentive and/or hyperactive/impulsive symptoms in children diagnosed with ASDs. The current consensus on this issue emphasizes careful differential diagnosis. The same is true of behavior disorders, which are often diagnosed in the population and which may be more appropriately characterized as sequelae of the ASD diagnosis itself, rather than true comorbid conditions. Appendix H provides a number of guidelines for accurate differential diagnosis.

3.4.4 Demographic Factors, Race, and Gender

Recent epidemiological studies have found no association between autism spectrum disorders and social class or race/ethnicity. While some studies have found somewhat higher rates of autism among families with higher incomes, this has been attributed to these families' greater access to diagnoses (CDC, 2006). Autism spectrum disorders affect boys more than girls. Reported ratios average around 3.5 or 4 to 1 (Fombonne, 2003; Lord, Schopler, & Revicki, 1982; Volkmar, Szatmari, & Sparrow, 1993 in Volkmar, Lord, Bailey, Schultz, & Klin, 2004).

3.5.0 Empirically Supported Practices

3.5.1 Early Identification, Assessment, and Diagnosis

The professional literature clearly supports the efficacy of early identification and treatment. Early diagnosis and intervention lead to improvements in functional level (American Academy of Pediatrics, 2001). Evidence suggests that interventions designed to improve functioning in children with ASDs are likely to be more effective with younger children (Committee on Children with Disabilities, 2001; Campbell, Schopler & Hallin, 1996; Rapin, 1997; Volkmar, Cook, Pomeroy, Realmuto & Tanguay, 1999). Moreover, early treatment results in a better long-term prognosis (Lord, 1995), whereas treatments delivered at older ages appear to have somewhat diminished returns (Mars, Maulk & Dowrick, 1998). Despite evidence that children can be reliably diagnosed at increasingly earlier ages (Charman & Baird, 2002), on average, children do not receive a diagnosis until reaching school age (Yeargin-Allsopp, et al., 2003). Significant opportunities for gains in functioning may be lost by delaying diagnosis, with costly effects for children, families, and states.

3.5.2 Cost Benefits of Providing Early Intensive Behavioral Intervention

Cost-benefit studies suggest that the gains made by children who receive early diagnosis and effective treatment outweigh future costs associated with greater disability (Jacobson, Mulick & Green, 1998; Jacobson & Mulick, 2000; Jarbrink & Knapp, 2001). For example, Jacobson and colleagues (1998) estimated net savings to the state of Pennsylvania by using early intensive behavioral intervention (EIBI). They first calculated the average cost benefit of providing a public K-12 education to a typically developing child. Career income to age 55 minus the cost of education resulted in a \$1.6 million benefit. According to this model, after providing EIBI and subtracting its cost, a child who achieved typical functioning would save the state \$1.5 million. The cost to Pennsylvania for a child who received EIBI and achieved “partial effects” to age 55 (calculated as cost of services for 52 years less income from supported work) was \$3.4 million. The cost to the state for a child receiving no EIBI (and presumably making no functional gains and holding no employment) was approximately \$4.4 million. Thus even partial effects (some functional gains) brought about by early intensive behavioral intervention recouped roughly \$1 million over the cost of delivering the services.

In children who may eventually develop comorbid psychiatric disorders, early intervention is especially warranted, as total costs of treatment to this population are compounded by the high cost of delivering inpatient and outpatient psychiatric care (Mandell, Cao, Ittenbach & Pinto-Martin, 2006).

A recent review of early detection and intervention literatures concludes:

...Delivering interventions for more than 20 hours weekly that are individualized, well planned, and target language development and other areas of skill development significantly increases children’s developmental rates—especially in language—compared with no or minimal treatment...Early intervention in autism needs to be seen as similar to teaching language to deaf children or to teaching mobility and Braille to blind children—a necessary, publicly funded, rehabilitative service, without which outcomes cannot be meaningfully discussed (Bryson, Rogers, & Fombonne, 2003, p. 510-511).

3.6.0 Service Challenges for Children with ASDs

States now confront considerable challenges serving children diagnosed with autism spectrum disorders. The challenges intensify with co-existing mental health diagnoses. In the face of increased prevalence—for whatever reason—and the bright line rule of early and intense intervention, public service agencies responsible for funding intervention and treatment must “respond in accordance and make efforts to identify children early and provide specialized services immediately” (National Research Council, 2001).

Given this mandate, it is curious that so little research has been conducted on service delivery to children with ASDs generally, and to dually diagnosed children specifically. There are no articles currently available that focus explicitly on delivering services to children with ASDs and co-occurring psychiatric diagnoses. However, the few existing studies on services to children with ASDs include some descriptive information on

psychiatric diagnoses. Existing studies address the following three issues: age at diagnosis, access and service use, and medical expenditures for children with ASDs.

3.6.1 Factors Associated with Age at Diagnoses

In a Pennsylvania survey of 969 caregivers of children with ASDs, Mandell and colleagues (2005) found that the average age of diagnosis for children with autism was 3.1 years, 3.9 years for PDD NOS, and 7.2 years for Asperger's disorder. Children who lived in a rural area or came from a "near poor" family were diagnosed later than other children. Children displaying severe language deficits, hand flapping, toe walking, and sustained odd play were likely to receive an earlier diagnosis than children not displaying these symptoms. Conversely, oversensitivity to pain and hearing impairment slowed the diagnostic process. Children with four or more primary care physicians received a diagnosis 0.5 years later than other children. Conversely, children who were sent by their pediatrician to a specialist received diagnoses 0.3 years sooner. Continuity in pediatric care and access to specialists are major implications of the study. Importantly, the study also found that (at least in Pennsylvania) children were diagnosed, on average, earlier than reported in past studies.

In another study of factors affecting age at which autistic disorder is diagnosed among Medicaid-eligible children, Mandell and colleagues (2002) found that white children, on average, received an autism diagnosis at 6.3 years compared to 7.9 years for black children. The authors theorized that observed discrepancies in time to diagnosis are the result of differences in help-seeking, advocacy, and support in white versus African American communities. Moreover, the authors speculate that clinician behavior may have contributed to longer waits for diagnoses among African American children.

3.6.2 Access and Service Use

In a study of access and service use by children with ASDs in a state Medicaid managed care plan (TennCare), researchers found that while service use increased over time (from FY 1995 to 2000), rate of service was only one tenth of what should be expected based on population estimates. Over time, the mean number of service days declined (by 40%), and children received different types of treatment. "Day treatment vanished and medication and case management increased disproportionately to the number of children served" (Ruble, et al., 2005). The authors attribute low service rates to providers not using ASD codes for claims, to parents seeking services through the educational system rather than behavioral health system, and to the managed care incentive to reduce cost by disallowing treatment on the basis that autism is not a proven biologically-based disorder.

In a more general study of access to specialty medical care for children with mental retardation, autism, and other special health care needs, Brandeis University researchers (Kraus, Gulley, Sciegaj, & Wells, 2003) found that parents of children with autism had the greatest difficulty (compared with parents of children with MR and a contrast group) accessing specialty medical care for their children. In other words, having autism was the biggest single predictor of encountering health plan-based access problems. One encouraging finding from this study is that children with primary or secondary Medicaid

coverage—including the children with autism—fared better than children who were not Medicaid eligible.

3.6.3 Medical Expenditures

In a study of Medicaid expenditures in one large Pennsylvania county (Mandell, et al., 2006), children diagnosed with autism spectrum disorders had expenditures 10 times those of other Medicaid-eligible children. Authors attributed this considerable discrepancy in expenditures to the cost of inpatient hospitalization for children with ASDs. They were unable to determine if those children who were hospitalized could have been treated in a less restrictive, and less costly setting. When the costs of inpatient utilization were controlled, children with ASDs still had more than two times the expenditures of children with mental retardation (MR) and children in a comparison group, primarily because children with ASDs had greater utilization of outpatient psychiatric services. Ambulatory care expenditures (routine visits to primary care physicians) among children with ASDs were only slightly higher than the general Medicaid-eligible sample, and lower than children with in the sample with mental retardation. This finding suggests a need for greater coordination of care by primary care physicians. Appropriate primary care visits would likely reduce inpatient and outpatient hospitalization and save Medicaid monies.

3.6.4 Dual Diagnoses

The above study, which compared children with ASD diagnoses, children with mental retardation, and all other Medicaid-eligible children in large Pennsylvania county, found that children with ASDs received considerably more psychiatric and developmental diagnoses than did other children (1.4 additional psychiatric diagnoses among children with ASDs, compared to 0.8 for children with mental retardation, and 0.2 for other Medicaid-eligible children). The predominant diagnoses given to children with ASDs were attention deficit disorder (29.6%) and oppositional defiant disorder (ODD) (23.9%). Conduct disorder (17.4%) and affective disorders (17.7%) were also common. By contrast, children with MR and other children in the sample were diagnosed most commonly with affective disorders (18.7% and 6 %, respectively). While the authors acknowledge that sleep and tic disorders, anxiety and depression, and hyperactivity may truly co-occur with ASDs, they speculate the broad range of other diagnoses given to the ASD population may reflect difficulty among clinicians in making the ASD diagnosis. They state, “Clinicians may assign other diagnoses because they mistake the symptoms of ASD for other disorders, or because they are required to assign a diagnosis in order to bill for a visit, and are not certain of the appropriate diagnosis” (Mandell et al., 2006, p. 482).

Summary of Literature Review

- Autism spectrum disorders are complex, neurodevelopmental disorders that require early, intensive behavioral intervention.
- No clear etiology exists, but there is strong evidence of genetic components.
- ASDs are four times more common in boys than girls.
- ASD prevalence is 60 in 10,000 or 6 in 1,000 children.
- Depressive and anxiety disorders are likely the most common co-occurring mental health disorders, but children with ASDs may be diagnosed disproportionately with attention deficit and oppositional behavior disorders.
- No one treatment approach has been validated for all children.
- Early, intensive, comprehensive behavioral approaches show greatest efficacy and may result in significant cost savings for states.
- In two studies, African American children, “near poor” children, and rural children were diagnosed more slowly than were other children.
- In comparative studies of access to specialty care, children with autism were more likely to encounter problems accessing appropriately trained providers than were children with MR.
- In a study of Medicaid expenditures in a large Pennsylvania county, children with ASDs had higher expenditures than children with mental retardation or other Medicaid-eligible children due to greater inpatient and outpatient utilization. Children with ASDs had lower than expected ambulatory care expenditures, suggesting the need for greater coordination of care by primary care physicians.

4. OVERVIEW OF CURRENT AUTISM SPECTRUM DISORDER WAIVER PROGRAMS

4.1.1 Autism Waivers

In recent years, states have begun to recognize the particular difficulties of serving children with autism spectrum disorders. These challenges are due in part to separate funding streams for developmental disabilities and mental health. To streamline service provision and to provide appropriate long-term services, Wisconsin, Indiana, Colorado, and Maryland have passed autism-specific waiver mechanisms. Massachusetts passed an autism waiver early in 2006; the state is in the process of establishing administrative responsibility and defining eligibility requirements.

Of the autism waivers currently in use, Wisconsin's is the most inclusive. It covers children with all autism spectrum disorders rather than limiting coverage only to children with autism. Children under age eight can receive three years of face-to-face services at 35 hours/week. Children and youth, aged 8-22, receive \$10,000 annually—to be spent on required services (OT, speech, education supports). Parents must qualify for Medicaid; otherwise, eligibility may be established through the TEFRA/Katie Beckett option (see below). The Katie Beckett option exempts the family's income from the Medicaid eligibility determination so that children with long-term disabilities or complex medical needs may be maintained with their families. Wisconsin's autism waiver also mandates that intensive services are coordinated through the schools and that providers meet state qualifications. (See Section 8.0, Recommendations, for more details on Wisconsin's restructure of Children's Long Term Care). Following are outlines of each state autism waiver.

4.1.2 Wisconsin

Administering Agency: Department of Health and Family Services

Age Range: 0-22 years

- Ages 0-8: The children are eligible for intensive face-to-face services for a maximum of 35 hours a week for three years.
- Ages 8-22: Child is allocated approximately \$10,000 annually to acquire a variety of services available under the waiver. Services include OT, speech, case management, education supports and respite care.

Number of Slots Available: Approximately 1000

Eligibility: Children on the Autism Spectrum

Financial: Must qualify for Medicaid services or the child can be admitted through the Katie Beckett eligibility determination (the family's income is not used to determine Medicaid eligibility for children with long-term disabilities or complex medical needs who are living with their families).

Coordination with Education: Intensive Services must be coordinated with relevant educational services through the public schools.

Provider Qualifications: The state has established provider qualifications for lead therapists, senior therapists and line staff.

Website: <http://www.dhfs.state.wi.us/bdds/clts/autism/autismqa1.htm>.

4.2.0 Indiana

Administering Agency: Center for Medicare and Medicaid Services and the Bureau of Developmental Disabilities

Age Range: 0-22 years

Number of Slots Available: Approximately 400

Eligibility: Children must have an autism diagnosis. The waiver does not cover children with PDD/NOS or Asperger's disorder.

Financial: The child must be Medicaid eligible. Parents' income is considered when determining eligibility.

Services Provided: Applied Behavior Analysis, behavior management, community education, respite care, occupational therapy, speech therapy and nutritional counseling

Provider Qualifications: The state has established provider qualifications for lead therapists, senior therapists and line staff.

4.3.0 Colorado

Administering Agency: Health Care Policy and Finance/Medicaid

Age Range: 0-6 years

Number of Slots Available: Approximately 75

Eligibility: Children must have an autism diagnosis. The waiver does not cover children with PDD/NOS or Asperger's disorder.

Financial: The child must be Medicaid eligible. Parents' income is taken into account when determining eligibility.

Services Provided: Behavior therapy, occupational therapy, speech therapy and psychological services.

Caps: Waiver services per child are capped at \$25,000/yr.

Provider Qualifications: The state has established provider qualifications for lead therapists, senior therapists and line staff.

4.4.0 Maryland

Administering Agency: Maryland Department of Education

Age Range: 0-21 years

Number of Slots Available: Approximately 900

Eligibility: Children with an autism spectrum diagnosis. The waiver does cover children with PDD/NOS and Asperger's disorder.

Financial: Financial eligibility is based on a child's income. Parental income is not considered.

Services Provided: Intensive individual support services including Applied Behavior Analysis, after school and extended daycare services, service coordination, respite care and family training.

Caps: Intensive individual support services are limited to 30 hours a week. Respite care is limited to 168 hours a year. Therapeutic integration is limited to 2-4 hours a day, five days a week

Provider Qualifications: All waiver service providers must be approved Medicaid providers and appropriately licensed or certified. The state has established provider qualifications for lead therapists, senior therapists and line staff.

Table 1: Summary of Current Autism Waiver Criteria

State	DHS/ Medicaid admin?	US DOE admin.?	Early childhood only?	Ages 0- 21?	PDD NOS/ Asperger's Disorder?	Autism only?	Parent income counted in eligibility?
Wisconsin	X			X	X		
Indiana	X			X		X	X
Colorado	X		X			X	X
Maryland		X		X	X		

4.5.0 TEFRA/Katie Beckett Option

The first national study of the Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option, also known as the Katie Beckett Option (Semansky & Koyanagi, 2004) found that while this option to allow children from near-poor and middle-income families to qualify for Medicaid has been available since 1982, only 20 states used the option in 2001. Furthermore, only ten of these states allowed children to qualify due to a mental health disability. Unlike HCBS waivers, under the TEFRA option, states cannot limit the number of slots or single out particular disabilities. To be eligible a) a child must have a physical or mental disability consistent with SSI standards; b) the disability must be expected to last at least one year or result in death; and c) the child must have severe functional limitations requiring the level of care provided in a hospital, an Intermediate Care Facility for the Mentally Retarded (ICF-MR), or a nursing home.

Ninety percent of children who qualify for TEFRA have a physical disability or mental retardation. The option has been used little for mental health disabilities. According to the Samansky et al., "States that are interested in increasing access to intensive services for children with severe disabilities might consider selecting the TEFRA option" (p. 340). However, as Kansas currently serves children with SED through a separate waiver, the utility of TEFRA would be limited for this population. TEFRA may hold promise for children with ASDs who are waiting for DD waiver slots, or children who do not qualify for either waiver. Used as an adjunct to HCBS slots, as it is used in Wisconsin, TEFRA could extend services to a larger proportion of children estimated to need services. Finally, a study of TEFRA in Minnesota found that it served a supplementary rather than primary insurance function, but more study is needed to determine its impact on Medicaid budgets.

5.0 KANSAS FINDINGS: AIMS DATA ANALYSIS

The following section of the report contains findings from an analysis of a 2004 extract of the Kansas Automated Information Management System (AIMS), the database of demographic, client status, and encounter information maintained for all persons served in Kansas community mental health centers.

5.1.1 Limitations of Data Sources

AIMS vs. MMIS

As discussed previously, due to an anticipated wait for MMIS data, researchers chose to utilize the AIMS database for this year of the study. Sole use of the AIMS database limited our ability to compare MR/DD and SED waiver usage or CDDO versus CMHC service types or intensities. Moreover using one year of cross-sectional data restricted our capacity to track, in a meaningful way, changes in CBCL scores, or to understand the conditions under which children ended treatment.

Diagnostic Categorization

Despite a professional consensus on the superiority of clustering together autism, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD NOS), researchers and clinicians alike remain bound to the latest classification of these disorders in the American Psychiatric Association's DSM-IV-TR (2004). The need for diagnostic standardization and the requirements of third-party payers necessitate use of one of five existing DSM pervasive developmental disorders. Although they are likely to change in the next iteration of the DSM, PDD's currently are grouped in the following manner:

- Asperger's disorder, Rett's disorder, and PDD NOS (299.8).
- autistic disorder (299.0)
- childhood disintegrative disorder (299.10)

Aside from debates about the comparatively uncommon occurrence and qualitatively dissimilar etiology of Rett's disorder versus the more symptomatically similar and epidemiologically common incidence of Asperger's and PDD NOS, the 299.8 code group also compromises the accuracy of data analysis. Researchers using large administrative and claims databases are unable to distinguish children with PDD NOS from those with Asperger's or Rett's disorder. In addition to the numeric frustration caused by this categorization, the implied similarity of diagnoses in this single code group also belies important qualitative distinctions. For example, PDD NOS is often a provisional diagnosis given when clinicians cannot or do not feel comfortable diagnosing a child with Asperger's Disorder. Greater specificity would allow researchers to track children who were initially given a PDD NOS diagnosis to determine whether these children are eventually diagnosed with Autism or Asperger's.

Primary Diagnosis Only

Another data limitation is posed by the fact that at least nine CMHCs report only primary diagnoses in the AIMS database. Therefore, the estimates discussed in the following tables and graphs underestimate the true number of children with ASDs served by Kansas CMHCs. The nine CMHCs who reported entering primary diagnoses only in an online

survey were: Wyandot, Crawford, Bert Nash, Center for Counseling and Consultation, Sunflower Centers, South Central, Pawnee, Comcare of Sedgwick County, and Sumner.

Lack of Statistical Certainty in Epidemiological and Psychiatric Literatures

Autism research is in its infancy. Few large-scale epidemiological studies of the population have been conducted. Even fewer studies of the prevalence of co-occurring psychiatric diagnoses exist. Therefore, the authors of this report wish to qualify the tables and graphs that follow, as they may overestimate the number of children that we would expect CMHCs to serve—particularly as we have no good data on the percentage of children with an ASD and co-occurring mental health issues.

Alternatively, we may have underestimated the true prevalence of autism spectrum disorders in Kansas. The authors read carefully the existing epidemiological literature and used best available estimates. However, until more methodologically sound large-scale studies are conducted, we cannot say with certainty that estimates reflect the true prevalence of children with autism or other ASDs. More reliable national data on dually diagnosed children are needed before an accurate approximation of the expected CMHC population can be rendered.

In the tables that follow, **60 in 10,000, or 6 in 1,000** children is used to estimate the total number of children with any autism spectrum disorder. The Center for Disease Control's recent estimate of **5.5 per 1,000** children is used to calculate the number of children in Kansas who have autism only.

5.2.0 Children with Autism Served by Kansas CMHCs

Table 2 displays the number and rate of children per 1,000 diagnosed with autism who were served by a Kansas CMHC in 2004. Unique children were selected who had primary or secondary diagnoses of autism during treatment, or who had primary or secondary diagnoses of autism at discharge. Figure 1 displays these same children as a percentage of the estimated population of children with autism.

**Table 2: Unduplicated Children with Autism Served by Kansas CMHCs:
Number and Rate per 1,000**

2004 Census estimated KS child population, 17 and under	Community Mental Health Center	N	Autism per 1,000 rate
2,390	Iroquois	2	0.8
6,611	Franklin	4	0.6
12,053	Four County	6	0.5
8,717	Cowley	4	0.5
34,152	Area	13	0.4
21,114	Horizons	8	0.4
19,981	East Central	7	0.4
21,039	Central KS	7	0.3
8,280	Crawford	2	0.2
35,433	Pawnee	7	0.2
15,397	Southeast KS	3	0.2
41,863	FSGC	8	0.2
43,966	Wyandot	7	0.2
6,465	Sumner	1	0.2
19,599	Bert Nash	3	0.2
26,544	Guidance Center	4	0.2
21,808	High Plains	3	0.1
7,501	Miami	1	0.1
10,338	Kanza	1	0.1
127,012	Johnson	9	0.1
15,715	South Central	1	0.1
17,585	Prairie View	1	0.1
126,187	Comcare/FCS	5	0.0
11,418	CCC	0	0.0
5,396	FLC	0	0.0
5,363	Labette	0	0.0
11,564	SW Guidance	0	0.0
683,491	State	107	0.2

Source: AIMS Extract for calendar year 2004. Population Data Source: CC-EST2004-agesex-20: Annual Estimates of the Population by Selected Age Groups and Sex for Counties in Kansas: April 1, 2000 to July 1, 2004 (From: Population Estimates Program, U.S. Bureau of the Census; Release Date: August 11, 2005)

Table 3 and Figure 1 indicate that overall, the number of children with an autism diagnosis served by Kansas CMHCs in 2004 was quite modest. Figure 1 may overestimate the number of children with autism we would expect community mental health centers to serve due, as mentioned, to: 1) lack of statistical certainty regarding the prevalence of autism in the general population; 2) lack of certainty about the prevalence of other psychiatric disorders within the autism population; and 3) possible underreporting by CMHCs that enter only primary diagnoses in the AIMS database.

Figure 1: Percentage of Estimated Autism Population Served by Kansas CMHCs in 2004

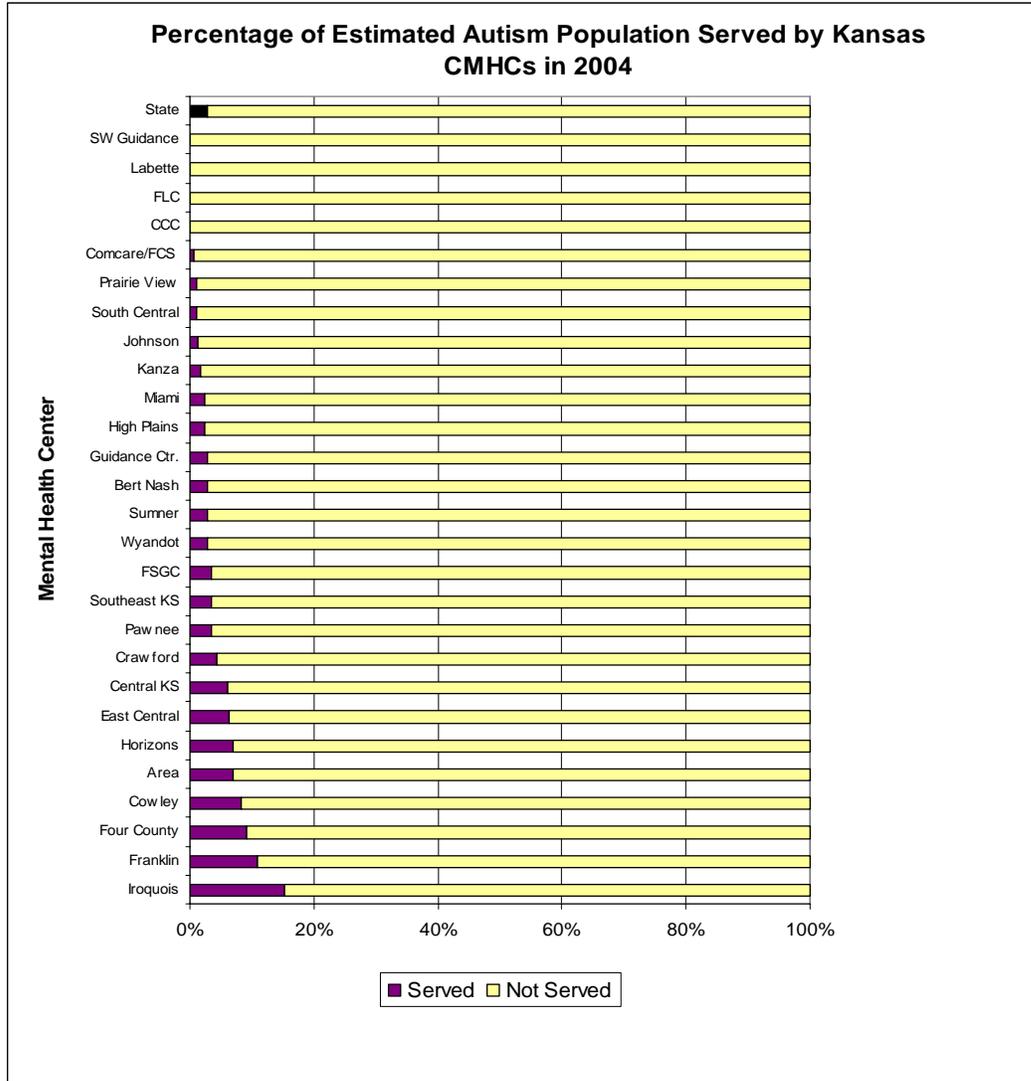


Table 3, below, displays the number and rate per 1,000 of children diagnosed with Asperger’s disorder, Rett’s disorder, or PDD-NOS who were served by Kansas CMHCs in 2004. Comparatively, Table 3 indicates that Kansas CMHCs served an almost 5:1 ratio of children with Asperger’s disorder, PDD-NOS, or Rett’s disorder versus children with autism. It is likely that the population of children with Rett’s disorder is negligible. Given

Table 3: Unduplicated Children with Asperger's Syndrome, PDD-NOS, or Rett's Syndrome Served by Kansas CMHCs: Number and Rate per 1,000

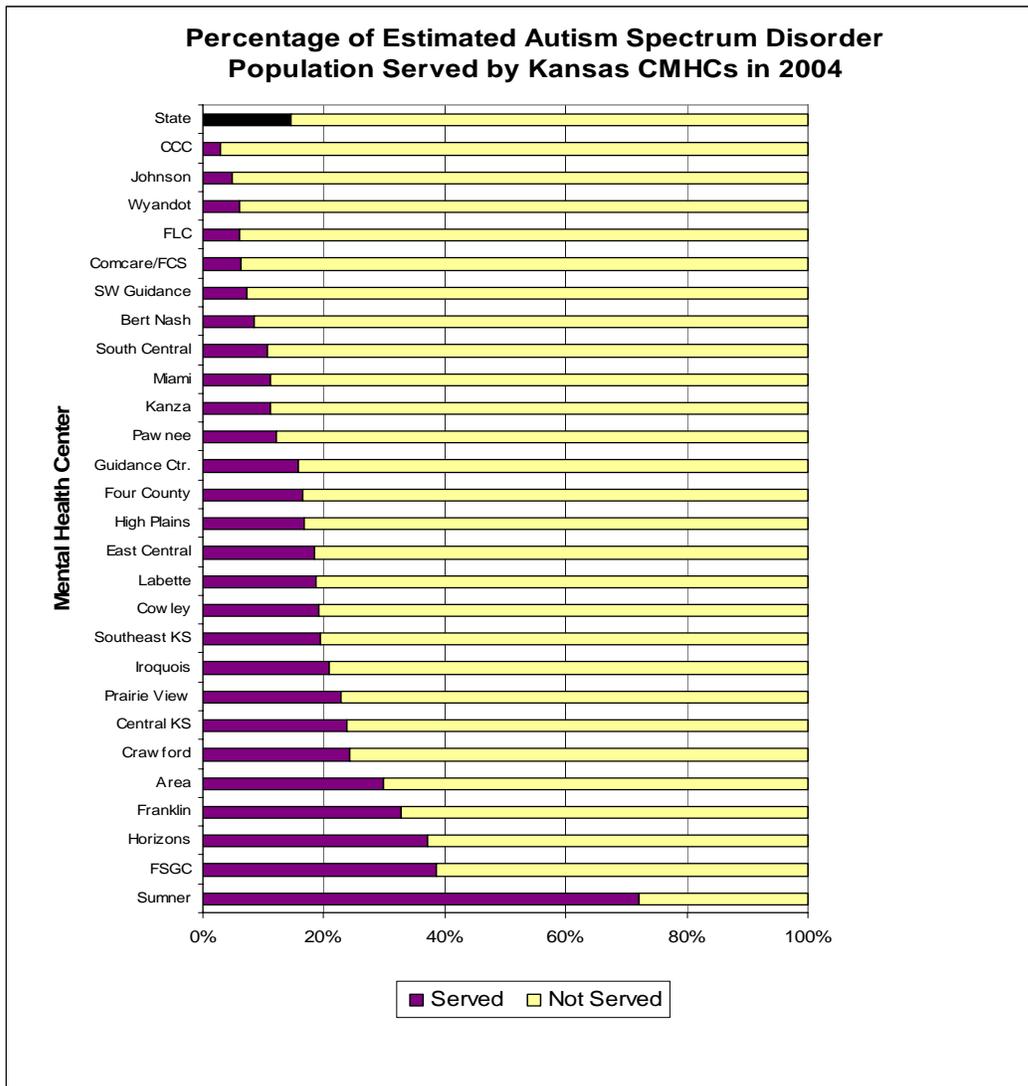
2004 Census estimated KS child population, 17 and under	Community Mental Health Center	N	Asperger's, PDD-NOS, & Rett's per 1,000
6,465	Sumner	27	4.2
41,863	FSGC	89	2.1
21,114	Horizons	39	1.8
34,152	Area	48	1.4
6,611	Franklin	9	1.4
17,585	Prairie View	23	1.3
8,280	Crawford	10	1.2
5,363	Labette	6	1.1
21,039	Central KS	23	1.1
15,397	Southeast KS	15	1.0
21,808	High Plains	19	0.9
26,544	Guidance Center	21	0.8
19,981	East Central	15	0.8
8,717	Cowley	6	0.7
10,338	Kanza	6	0.6
15,715	South Central	9	0.6
35,433	Pawnee	19	0.5
7,501	Miami	4	0.5
12,053	Four County	6	0.5
11,564	SW Guidance	5	0.4
2,390	Iroquois	1	0.4
5,396	FLC	2	0.4
19,599	Bert Nash	7	0.4
126,187	Comcare/FCS	43	0.3
127,012	Johnson	28	0.2
43,966	Wyandot	9	0.2
11,418	CCC	2	0.2
683,491	State	491	0.7

Source: AIMS Extract for calendar year 2004. Population Data Source: CC-EST2004-agesex-20: Annual Estimates of the Population by Selected Age Groups and Sex for Counties in Kansas: April 1, 2000 to July 1, 2004 (From: Population Estimates Program, U.S. Bureau of the Census; Release Date: August 11, 2005)

documentation of coexisting psychiatric disorders in this population, we would expect a significantly higher rate of service to this population by the CMHCs. Moreover, as many as 70% of children with autism may have mental retardation, which would qualify them for service from the CDDO system. This may explain the lower percentages of children with autism served in the CMHC system in 2004.

As there are no reliable data on the prevalence of the DSM-IV diagnostic category 299.8 (Asperger’s disorder, Rett’s disorder, and PDD NOS), we could not provide an estimate of estimated “other ASD” children in Kansas. Therefore, Figure 2 presents the *total population* of children diagnosed with an ASD (including autism) as a percentage of the current best population estimate (6 per 1,000) of children with any ASD. While Figure 2 is instructive, it must be interpreted with some caution for reasons previously discussed.

Figure 2: Percentage of Total ASD Population Served by Kansas CMHCs in 2004



Perhaps most notable in these data are very low service rates by CMHCs in populous counties such as Johnson, Wyandotte, and Sedgwick. As discussed, this may be an artifact of AIMS data entry practice; at least two of these CMHCs (Wyandot and Comcare) may have recorded primary diagnoses only, thus excluding some children diagnosed primarily with other psychiatric diagnoses but secondarily diagnosed with an autism spectrum disorder. In addition, specialty providers in the Kansas City metro area such as the University of Kansas Autism and Asperger's Resource Center may divert some of the children and families who might otherwise seek services at Johnson and Wyandot County Community Mental Centers. In Sedgwick County, Heartspring School may divert some families. However, this population-based scenario is less likely in Sedgwick County, as Heartspring's admissions come from a national pool and it is DOE funded. Alternatively, children who live in better-funded school districts (like Johnson and Sedgwick) may receive more services through their schools than through CMHCs. Parents and CMHC staff attributed the high number of children served by Family Service and Guidance in Topeka to the diagnostic expertise of its child psychiatry staff.

Tables 4 and 5 present information on the service experiences of children receiving services in 2004.

Table 4: Service Demographics

	Children with Autism <i>n</i> =107	% or <i>M</i>	Children with Asperger's, Rett's Disorder, or PDD NOS <i>n</i> =491	% or <i>M</i>
Acuity (How quickly the person needs to be seen) ²				
Emergent	1	0.9	17	3.5
Urgent	2	1.9	22	4.5
Routine	91	85.0	361	73.5
Missing	13	12.1	91	18.5
Eligibility Supplemental Determination Benefits (E.g., SSI or SSDI)				
Not applicable	73	68.2	357	72.7
Eligible and receiving payments	20	18.7	57	11.6
Eligible not receiving payments	1	0.9	10	2.0
Potentially eligible	5	4.7	32	6.5
Determined ineligible by review	1	0.9	3	0.6
Determined decision on appeal	1	0.9	1	0.2
Missing	6	5.6	31	6.3
Calendar Year of Service Start				
2000 or prior	11	10.3	79	16.1
2001	5	4.7	37	7.5
2002	10	9.3	63	12.8
2003	20	18.7	89	18.1
2004	61	57.0	223	45.4

Table 5: Service Demographics, Continued

	Children with Autism n=107	% or M		Children with Asperger's, Rett's Disorder, or PDD NOS n=491	% or M
Population Density (based on Resident County)					
Frontier	4	3.7		10	2.0
Rural	10	9.3		46	9.4
Densely-settled rural	25	23.4		126	25.7
Semi-urban	35	32.7		113	23.0
Urban	33	30.8		194	39.5
Reason for Stopping Waiver					
Service plan goal met	2	1.9		4	0.8
Moved out of CMHC area	0	0.0		3	0.6
Family/youth choice	0	0.0		3	0.6
State hospital	0	0.0		2	0.4
Residential placement	0	0.0		3	0.6
Lack of cooperation/refusal to sign	1	0.9		0	0.0
Non-waiver or still on waiver	104	97.2		476	96.9
Length of Service * (Time from admission date to closing date)					
Under 3 months	7	6.7		23	4.8
3 to 6 months	15	14.4		26	5.4
6 to 12 months	8	7.7		42	8.8
12 to 18 months	0	0.0		15	3.1
18 to 24 months	2	1.9		12	2.5
2 to 4 years	1	0.9		14	2.9
4+ years	1	0.9		13	2.7
No closing date or still open	70	67.3		333	68.2
Discharge Reason					
Evaluation complete	4	3.7		14	2.9
Treatment complete (planned discharge)	5	4.7		29	5.9
Treatment not complete: agency decision	1	0.9		5	1.0
Treatment not complete: client decision	13	12.1		60	12.2
Transfer to alternative program	5	4.7		14	2.9
Client moved	5	4.7		28	5.7
Death/accident	1	0.9		0	0.0
No discharge reason or case still open	73	68.2		341	69.5

*Three children were excluded due to discrepancies in the date. The total number of children with autism for whom length of service information was available was 104.

5.2.1 Acuity

Acuity is defined in the following manner in the AIMS service manual.

- Emergent: services are needed immediately to meet the needs of an individual who is experiencing an acute psychiatric crisis which is at a level of severity that may meet requirements of hospitalization, or who, in the absence of immediate services, may require hospitalization. Mandated response time: 3 hours.
- Urgent: services required to prevent a serious complication or deterioration in the individual's health and cannot be delayed without imposing undue risk on the individual's well-being and if not promptly treated could become an emergent situation. Mandated response time: 72 hours.
- Routine: non-crisis in nature. Mandated response time: within 10 working days of the person's first contact with the CMHC.

Intake and assessment staff judged most children's need for services to be routine. A negligible percentage of children with autism were deemed acutely in need of treatment. Eight percent of children with an ASD other than autism necessitated emergent or urgent treatment.

5.2.2 SSDI Eligibility

Of the children with an ASD other than autism, a small percentage (2 %) were eligible for SSI/SSDI but not receiving it. Only one percent of children with autism were eligible but not receiving disability assistance. Twenty children with autism (18.7 %) and 57 children (11.6%) with another ASD were receiving SSDI.

5.2.3 Calendar Year of Service Start

Calendar year of service start indicates the year the child began receiving services through a CMHC. Data are cross-sectional and descriptive; they do not indicate a trend. Of children with autism in this sample, more than half (57%) began receiving services in 2004; 43% began receiving services in previous years. Similarly, 55% of children with another ASD began services at the CMHC prior to 2004, while 45.4% began in 2004. Larger numbers of children receiving services in 2004 simply indicates that the dataset was drawn from an 2004 extract of AIMS, not that the number of children receiving services has increased dramatically in 2004. As AIMS recording practices have become more uniform in recent years, several years of longitudinal data will be available in year two of this study. Longitudinal data will allow for a fuller examination of service utilization.

5.2.4 Population Density

Children with autism and other ASDs appear to be distributed in a geographically representative manner. No significant differences between the two groups are observed.

5.2.5 Reason for Stopping Waiver

Of the few children for whom we have information about waiver discontinuation, two children with autism and four children with other ASDs met their service plan goals.

Other reasons—moving out of CMHC catchment, choosing to stop services, becoming hospitalized or placed in residential treatment, and refusing to cooperate with services—are recorded for small numbers of children. Information about waiver discontinuation is unavailable for the remaining children. Either they never received services, or they continued to receive services.

The next section, on client functioning, provides a more detailed view of service usage.

5.2.6 Length of Service

Of those children with a closing date (34 children with autism; 145 with other ASDs), almost all children with autism (88%) ended services in less than 12 months, while 63% of the children with ASDs who discharged did so within one year. However, nearly 70% of both total groups were either still receiving services or had no reported closing date.

5.2.7 Reason for Discharge

Consistent with the information on “length of service,” nearly 70% of both groups had no closing service date, which indicates that they have not yet discharged or that this information was not recorded. Of children with autism or other ASDs in 2004, 12% ended treatment before it was complete, while just 4.7% of those with autism and 5.9% of those with another ASD ended treatment due to a planned discharge. Of children who were discharged, 40% ended treatment before it was complete, while 14.7% of those with autism and 19.3% of those with another ASD ended treatment due to a planned discharge.

Summary of Children Served by Kansas CMHCs

- In 2004, Kansas CMHCs recorded service to 107 children with autism and 491 children with Asperger's disorder, PDD NOS, or Rett's disorder.
- The total population of children with ASDs served in CMHCs was 591. (Seven were diagnosed with both autism and another ASD).
- Using best current estimates of ASD prevalence (6 children in 1,000), Kansas CMHCs served less than 20% of the children expected to have an autism spectrum disorder. (This may be an underestimate due to AIMS data recording practices and lack of certainty regarding prevalence rates.)
- As many as 70% of children with autism may have mental retardation, which would qualify them for service from the CDDO system. This may explain the lower percentages of children with autism served in the CMHC system in 2004.
- CMHCs in the three most populous Kansas counties—Johnson, Sedgwick, and Wyandotte—reported very low rates of service to the ASD population. Specialty providers and better funded school districts may account for some service diversion. (AIMS data reporting practices may also account, in part, for these low numbers.)
- Few children with autism or another ASD were judged to have an urgent or emergent need for mental health services. Acuity was noted as “routine” in the preponderance of cases.
- Approximately 18.7% of children with autism and 11.6% of children with another ASD received SSDI. One child with autism and ten children with other ASDs were eligible but not receiving SSDI at the time of admission.
- Of children with autism in 2004: 12% ended treatment before it was complete, 4.7% transferred to another program, 3.7% were discharged because their evaluation was complete, and 4.7% completed treatment.
- Of children with an ASD in 2004: 12% ended treatment before it was complete, 2.9% transferred to another program, 2.9% were discharged because their evaluation was complete, and 5.9% completed treatment.

5.3.0 Child Population Description

Tables 6, 7, and 8 present general demographic, educational, and child welfare status information for children with a diagnosis of an ASD who received CMHC services in 2004.

Table 6: General Demographics

	Children with Autism <i>n</i> =107	% or <i>M</i>	Children with Asperger's, Rett's, or PDD NOS <i>n</i> =491	% or <i>M</i>
Child Gender				
Female	18	16.8	75	15.3
Male	89	83.2	416	84.7
Child Race/Ethnicity				
Amer. Indian/Alaska Native	1	0.9	6	1.2
Asian	2	1.9	2	0.4
African Am, Black, Non Hispanic	4	3.7	34	6.9
Native Hawaiian/Pacific Islander	0.0	0.0	1	0.2
White	77	72.0	369	75.2
Other/Unknown	10	9.3	18	3.7
Missing	13	12.1	61	12.4
Age Grouping at Time of Admission				
Under age 1	0	0.0	1	0.2
1 through 3	18	16.8	31	6.3
4 through 6	18	16.8	117	23.8
7 through 9	23	21.5	128	26.1
10 through 12	27	25.2	107	21.8
13 through 15	15	14.0	76	15.5
16 through 17	5	4.7	28	5.7
18 and older	1	0.9	3	0.6
Mean Age		9.2		9.6
Income Group				
0	9	8.4	52	10.6
1-19,999	32	29.9	148	30.1
20,000-39,999	21	19.6	84	17.1
40,000-59,999	6	5.6	29	5.9
60,000-88,887	2	1.9	15	3.1
88,888 +	2	1.9	8	1.6
No answer	33	30.8	153	31.2
Missing	2	1.9	2	0.4

Table 7: Educational Information

	Children with Autism <i>n=107</i>	% or M	Children with Asperger's, Rett's, or PDD NOS <i>n=491</i>	% or M
Last Educational Placement				
N/A (not in school)	7	6.5	38	7.7
Institutional Instruction	1	0.9	7	1.4
Partial Hospitalization/Residential school	1	0.9	4	0.8
Special Education (more than 60% of school day)	47	43.9	148	30.1
Special Education (less than 60% of school day)	6	5.6	82	16.7
Regular class with Spec Ed services	14	13.1	59	12.0
Regular class with Spec Ed consultation	3	2.8	17	3.5
Regular class	9	8.4	73	14.9
Home based instruction from school district	0	0.0	2	0.4
Home schooling (not by school district)	3	2.8	2	0.4
Preschool	4	3.7	30	6.1
Suspended	0	0.0	2	0.4
Drop out	0	0.0	1	0.2
Graduated	2	1.9	7	1.4
Other	5	4.7	16	3.3
Missing	5	4.7	3	0.6
Last School Attendance				
Not attending	6	5.5	26	5.3
Infrequent (1-59%)	1	0.9	5	1.0
More than not (60-89%)	2	1.8	27	5.5
Regular (90-100%)	82	76.6	394	80.2
Unknown/NA	9	8.2	35	7.1
Missing	7	6.5	4	0.8
Last Academic Performance				
Above average (A/B)	16	15.0	70	14.3
Average (C)	26	24.3	142	28.9
Below Average (D)	2	1.9	29	5.9
Failing (F)	0	0.0	3	0.6
Unknown/Not applicable	14	13.1	63	12.8
Missing	49	45.8	184	37.5

Table 8: Child Welfare Status

	Children with Autism <i>N=107</i>	% or <i>M</i>	Children with Asperger's, Rett's, or PDD NOS <i>n=491</i>	% or <i>M</i>
Child Welfare Status				
SRS and out of home placement	8	7.5	47	9.6
SRS but lives at home	1	0.9	1	0.2
SRS supervise but not custody	3	2.8	11	2.2
No JJA or SRS involvement	90	84.1	408	83.1
JJA and out of home	0	0.0	1	0.2
Under JJA supervision but not custody	0	0.0	1	0.2
Missing	5	4.7	22	4.5

Most surprising in these descriptive data are the similarities between groups. For example, Asperger's disorder generally is diagnosed later than autism. We might thus expect to find a difference in the average age of children with autism and those with other ASDs, but the mean age at intake was nine for both groups. Gender ratio, race/ethnicity, and income were almost identical for the two groups.

Children differed chiefly in educational services. As anticipated, a larger percentage of children with autism were receiving special education programming more than 60% of their school day (43.9% vs. 30.1%), whereas a larger percentage of children with other ASDs were integrated in educationally typical classrooms with no special education services (14.9% vs. 8.4%). However, a greater percentage of children with autism were placed in typical classrooms with special education services or consultation (15.9% vs. 15.5%) than children with ASDs. The non-autism group also had a slightly elevated likelihood of out-of-home placement. These removals from the home may have been due to behavioral problems exhibited by this group, or to parents seeking services for their children by relinquishing custody to the state. This area deserves greater scrutiny.

Summary of Child Population Data

Child population data indicate that children with autism:

- Were predominantly white (72%).
- Were predominantly male (ratio 5:1).
- Were, on average, 9.2 years old.
- Predominantly lived in families with a reported income under \$40,000 (58%).
- Overall, had no JJA involvement and little SRS involvement— with 84% experiencing no involvement in either system and eight children being placed in out-of-home placement.
- Were attending public schools, with almost half (47%) receiving special education more than 60% of the school day.
- Largely attended school regularly—90-100% of the time (77%) and got A's, B's, and C's (41.2%).

Children with a diagnosis of Asperger's disorder, Rett's disorder, or PDD NOS:

- Were predominantly male (ratio 5:1).
- Were predominantly white (75.2%) and African American (6.9%).
- Were, on average, 9.6 years old.
- Predominantly lived in families with a reported income under \$40,000 (58%)
- Were significantly more likely to be in regular education classes than children with autism (14.9% vs. 8.4%).
- Were less likely than children with autism to have special education services more than 60% of the school day (30% vs. 44%).
- Largely attended school regularly—90-100% of the time (80%) and made A's, B's, and C's (49.1%).
- Were more likely to be in an out-of-home placement than children with autism (9.6 vs. 7.5%).
- Overall, had similar percentages (83% vs. 84%) of children with no JJA or SRS involvement. However, one child was involved with JJA. This deserves further scrutiny.

5.4.0 Comorbid Psychiatric Diagnoses

To provide a clearer picture of co-morbid psychiatric diagnoses, we selected from our original data sets of 107 children with autism and 491 children with another ASD, those children with primary psychiatric diagnoses. These subsets consisted of 77 children with autism and 252 children with another autism spectrum disorder.

5.4.1 Children with Secondary Autism Diagnoses

Of 107 in the original data set, 77 had a primary diagnosis of autism. Table 9 lists the primary diagnoses of the remaining 30 children who were diagnosed with autism secondarily. The three most common co-occurring diagnoses appear in bold.

Table 9: Primary Diagnoses of Children Secondarily Diagnosed with Autism

Diagnoses	Frequency <i>n=30</i>	Percent
Attention Deficit/Hyperactivity Disorder	8	26.7
PDD, Rett's, Asperger's	6	20.0
Disruptive Behavioral Disorders (Oppositional defiant disorder, conduct disorder, disruptive behavior disorder NOS)	5	16.7
Mood Disorders (Major depression, bipolar disorder, dysthymia)	3	10.0
Mental Retardation	2	6.7
Elimination Disorders	1	3.3
Other Disorders of Infancy, Childhood, Adolescence	1	3.3
Anxiety Disorders (Generalized anxiety disorder, phobias, panic disorder, PTSD, OCD)	1	3.3
Adjustment Disorders	1	3.3
Diagnosis missing	2	6.7
Total	30	100.0

The three most common co-occurring diagnoses in children secondarily diagnosed with autism were attention deficit disorders, presumably provisional diagnoses of other ASDs, and behavior disorders. Depressive disorders and mental retardation were primary diagnoses for only 6.7 % of this group. Given the high rate of comorbid mental retardation in this population, one might expect to see higher numbers of MR diagnoses; however, low numbers may reflect the fact that MR is not recorded as primary in CMHCs, since CMHCs require another DSM diagnosis in order to provide services.

Of the 77 children who had autism as a primary diagnosis, 23 had discharge information. Of those 23, 22 or (96%) had autism as the primary diagnosis at discharge. The remaining child had disruptive behavioral disorder as the primary diagnosis at discharge. This may indicate that once given, autism is a fairly stable diagnosis.

5.4.2 Children with Secondary ASD Diagnosis

Of the 491 children in our original data set who had an ASD other than autism as a diagnosis at any point in 2004, ASD was the primary diagnosis for 48.7%, or 239 children. Table 10 lists the primary diagnoses of the remaining 252 children who were diagnosed secondarily with Asperger's disorder, Rett's, or PDD NOS. The three most prevalent co-occurring disorders appear in bold.

Table 10: Primary Diagnoses of Children Secondarily Diagnosed with 299.8

Diagnoses	Frequency <i>n</i> =252	Percent
Attention Deficit/Hyperactivity Disorder	100	39.7
Disruptive Behavioral Disorders (Oppositional defiant disorder, conduct disorder, disruptive behavior disorder NOS)	49	19.4
Mood Disorders (Major depression, bipolar disorder, dysthymia)	35	13.8
Adjustment Disorders	19	7.5
Anxiety Disorders (Generalized anxiety disorder, phobias, panic disorder, PTSD, OCD)	13	5.2
Other Disorders of Infancy, Childhood, Adolescence	11	4.4
Impulse Control Disorders	7	2.8
Schizophrenia	2	0.8
Communication Disorders	2	0.8
Other Psychotic Disorders	1	0.4
Sexual and Gender Identity disorders	1	0.4
Sleep Disorders	1	.4
Tic Disorders	1	0.4
Elimination Disorders	1	0.4
Abuse - focus on victim	1	.4
Autism	1	.4
Mental Retardation	1	0.4
Learning Disorders	1	0.4
Diagnosis missing	5	2.0
Total	252	100.0

Consistent with a recent study of a large administrative database in Pennsylvania (Mandell et al., 2006), the predominant co-occurring diagnoses given to children with ASDs were attention deficit/hyperactivity disorder (39.7%), disruptive behavior disorders

(19.4%), and mood disorders (13.8%). In the Pennsylvania study, two comparison groups—children with MR and Medicaid-eligible children who neither had MR or ASDs—were more often diagnosed with affective disorders rather than attention and behavior disorders. While depression and anxiety are likely the “truest” comorbid conditions associated with ASDs (Tidmarsh and Volkmar, 2003), attention and behavioral disorders have become commonplace features of the dual diagnosis landscape. Experts (Mandell et al., 2006) speculate that while these diagnoses may truly co-occur with ASDs, clinicians also may assign these diagnoses in error or because they have to assign a psychiatric diagnosis in order to bill for services.

Similar diagnostic quandaries appear to exist in Kansas hospitals, and perhaps by extension, in CMHCs. A previous study of state and private psychiatric hospital use by children in Kansas (Walter, Davis, & Petr, 2005) found dramatic variation in the kinds of diagnoses children received. For example, ADHD appeared to be a frequent diagnosis at the University of Kansas Medical Center but not Coffeyville Regional Medical Center, where instead, many children received bipolar disorder diagnoses. The most plausible explanation was variability in clinician practice. This phenomenon warrants further investigation, as it may also affect the population of children with ASDs.

Of the 239 children who had as their primary diagnosis an ASD other than autism, 66 had discharge information. Of those 66 children, 58 or (88%) retained their primary ASD diagnosis at discharge, compared to 96% of children diagnosed with autism. This suggests slightly more diagnostic fluctuation among children with other ASDs.

5.4.3 Discharge information for children with secondary autism or ASD diagnoses

To get a sense of the process of diagnostic evolution, we examined discharge information for children who were secondarily diagnosed with autism or an ASD—that is, children who primarily had other psychiatric diagnoses—to see if children with other disorders would receive a primary autism or ASD diagnoses at discharge. Of the 30 children with autism as a secondary diagnosis, 11 had discharge information.

For three of those children, the diagnosis changed as follows:

- “Missing” changed to autism.
- PDD NOS changed to autism.
- Disruptive behavior disorder changed to autism.

Although a very small number, these changes would seem to indicate that PDD NOS and perhaps other diagnoses are given provisionally, until an autism diagnosis can be made. A different “pattern” can be observed with the ASD group. Of 252 children secondarily diagnosed with another ASD, 87 had discharge information. For eight children, the diagnosis changed as follows:

- Two children with “disorders of childhood/infancy not otherwise specified” changed to ADHD.
- One child with a “disorders of childhood/infancy” diagnosis changed to PDD NOS.

- Impulse control disorder changed to ADHD.
- Disruptive behavior disorder changed to ADHD.
- ADHD changed to psychotic disorder NOS.
- OCD changed to anxiety disorder.
- ADHD changed to PDD NOS.

While these changes, in most cases, were not in the predicted direction (from ADHD to an ASD for example), they provide a glimpse into the rule-out process. That so many disorders changed to ADHD may be a sign that upon initial diagnosis, clinicians are gathering data from the two collateral sources required to corroborate clinical impressions. However, given cautions about spurious ADHD diagnoses in the ASD population, the prevalence of the ADHD diagnosis warrants further examination.

5.5.0 Functional Levels of Children Diagnosed with Autism or Other ASD

Table 11: Child Functioning

	Children with Autism N=107	% or M	Children with Asperger's, Rett's, or PDD NOS n=491	% or M
Prior Hospitalization				
None	98	91.6	393	80.0
State Mental Health Hospital	4	3.7	18	3.7
Private Psychiatric Hospital	2	1.9	48	9.8
Out-of-Home Crisis Stabilization	1	0.9	4	0.8
General Hospital Psychiatric Ward	1	0.9	21	4.3
Residential mental health ward w/in state correctional facility	0	0.0	2	0.4
Missing	1	0.9	5	1.0

5.5.1 Prior Hospitalization

As depicted in Table 11, seven (of 107) children with autism (6.5%) were hospitalized in a state hospital, a private psychiatric hospital, or on a general hospital ward, while one child was stabilized by crisis intervention services. Overall, a high percentage of children with autism (91.6%) did not experience prior hospitalization. By contrast, 20% of children with other ASDs experienced some type of hospitalization, the largest group (48 or 9.8%) in private psychiatric hospitals.

5.5.2 Chronicity at End of Time Period

Figures 3, 4, and 5 depict the clinical chronicity of children with autism and other ASDs at the end of 2004 (or at discharge if the child exited during 2004). Clinical chronicity is determined by assessing clinicians. The term serious emotional disturbance (SED) refers

to a diagnosed mental health condition that substantially disrupts a youth’s ability to function socially, academically, and emotionally.

Persons diagnosed with severe and persistent mental illness (SPMI) are persons aged 18 and older who have a current DSM-IV designated mental illness diagnosis and experience substantial impairments in functioning due to the severity of their clinical condition.

Figure 3: SPMI/SED among Children with Autism

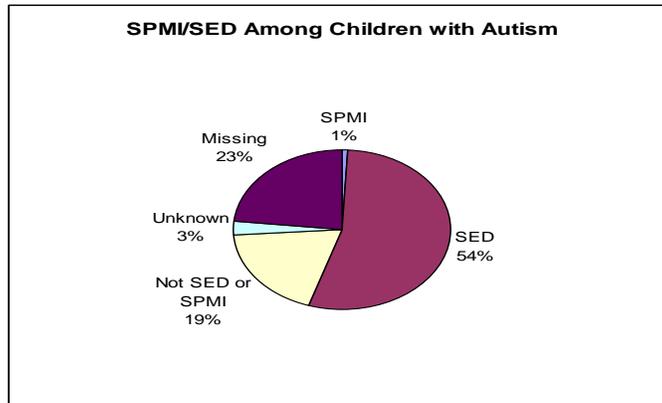
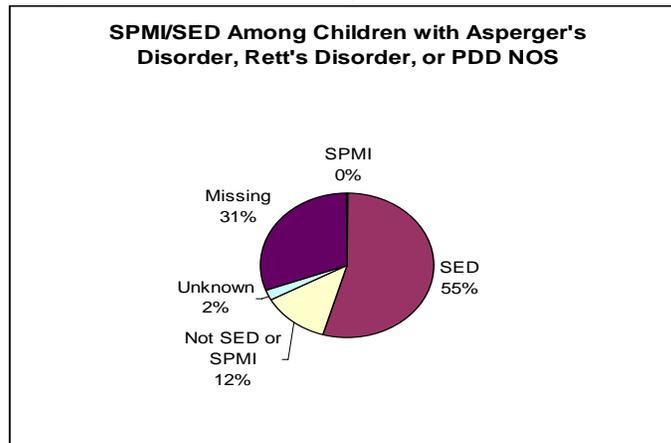


Figure 4: SPMI/SED among Children with other ASDs



The foregoing figures contain large amounts of unreported data, which underestimates the number of children and youth with SED or SPMI. Of the information available, 54% of children with autism and 55% of children with another ASD experienced serious emotional disturbance. One young adult with autism and one young adult with another ASD were considered SPMI. (This is not reflected in Figure 4 because one of 491 children appears as 0.2 %.) This would indicate that both young adults were 18 years old and met criteria for autism and a co-occurring serious and persistent mental illness. While SPMI and Asperger’s disorder frequently co-occur, the co-occurrence of SPMI and autism is less documented and represents an area for further inquiry.

Figure 5: Chronicity at End of 2004
(or at discharge if discharge occurred in 2004)

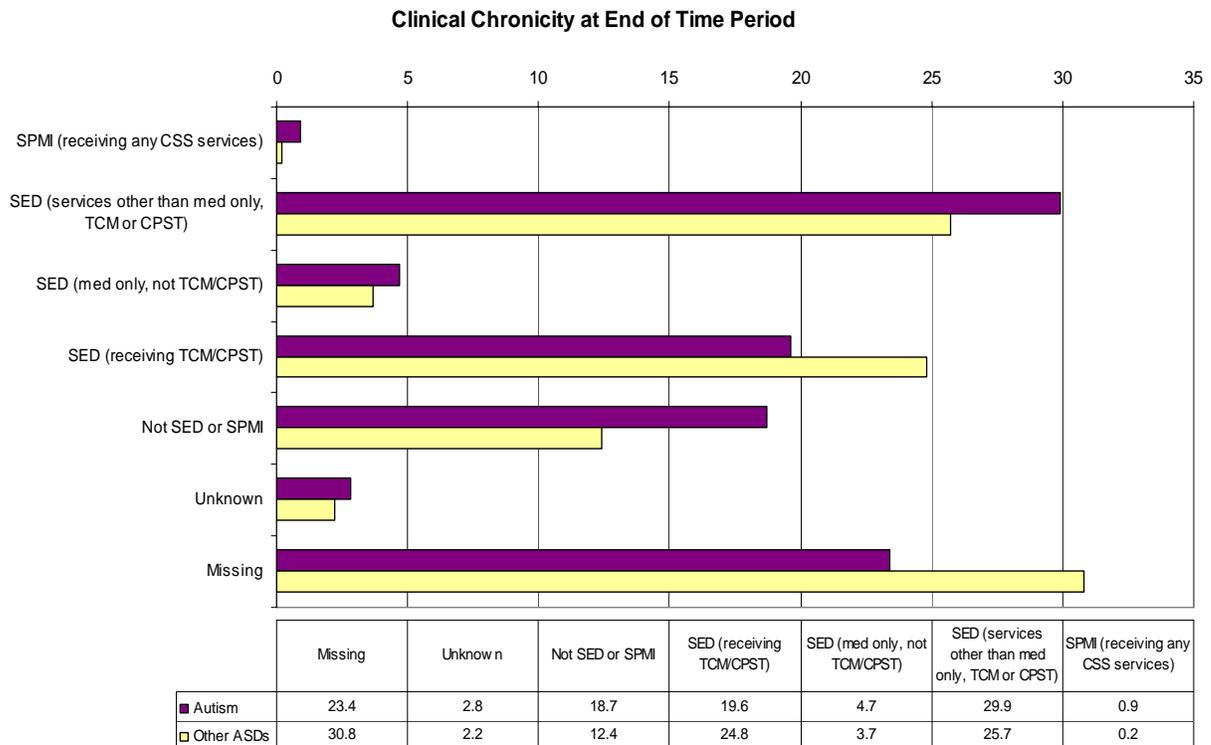


Figure 5 displays clinical chronicity at the end of the 2004 data collection period (or discharge if the child exited in 2004). Figure 5 indicates that the largest percentages of both groups (29.9 % of children with autism and 25.7% of children with other ASDs) were considered SED and received services other than medication management, targeted case management (TCM) or community psychiatric support treatment (CPST). The next largest group received TCM or CPST. Few children with autism (4, or 4.7%) or another ASD (18, or 3.7%) met criteria for SED and received only medication management through the CMHCs. This would seem to indicate that CMHCs were providing, to the best of their abilities, an appropriate array of services.

Finally, Table 13 illustrates functional levels at intake and discharge (if the child was discharged in 2004). Functional levels are based on the DSM Global Assessment of Functioning (GAF) scale. Noteworthy is the large percentage of children at intake (58.9% of children with autism and 46.2% of children with another ASD) with functional levels of 50 and under. This may indicate a discrepancy with acuity information presented earlier. It appears that more than half the children with autism and almost half the children with other ASDs present with very serious psychiatric problems and impairments in social or school functioning. Levels at closing are distributed in higher ranges of functioning, indicating the possibility of functional improvement in those children for whom information was available. However, again, large numbers of

unreported data compromise our ability to characterize functional levels at closing for all children in our sample.

Table 12: Functional Levels

Global Assessment of Functioning Score (GAF)	Children with Autism N=107	% or M		Children with Asperger's, Rett's, or PDD NOS n=491	% or M
Functional Level at Intake					
10 and under	1	0.9		1	0.2
11-20	5	4.7		5	1.0
21-30	6	5.6		17	3.4
31-40	19	17.8		51	10.4
41-50	32	29.9		153	31.2
51-60	30	28.0		194	39.5
61-70	8	7.5		45	9.2
71-80	1	0.9		4	0.8
Missing (all scores of 0 count as missing)	5	4.7		21	4.2
Functional Level at Closing					
10 and under	1	0.9		0	0.0
11-20	1	0.9		2	0.4
21-30	1	0.9		2	0.4
31-40	7	6.5		14	2.9
41-50	6	5.6		42	8.6
51-60	13	12.1		53	10.8
61-70	4	3.7		24	4.9
71-80	1	0.9		4	0.8
Missing (all scores of 0 count as missing)	73	68.2		350	71.3

Summary of Dual Diagnoses and Levels of Functioning

- Almost 30 % of children with autism and 40% of children with other ASDs had dual diagnoses of ADHD.
- Nearly 17% of children with autism and nearly 20% of children with other ASDs were dually diagnosed with disruptive behavioral disorders.
- Approximately 10% of children with autism and 13.8% of children with other ASDs were dually diagnosed with mood disorders.
- Few children with autism had MR diagnoses.
- Adjustment disorders also appeared with some frequency in the population of children with ASDs.
- Primary diagnoses appeared quite stable; once a child receives a primary diagnosis of autism or another ASD, they are likely to keep this diagnosis. However, children with ASDs experienced slightly more diagnostic change than did children diagnosed with autism.
- Only 6.5% of children with autism experienced some type of hospitalization, whereas 20% of children with other ASDs were hospitalized—most commonly in private psychiatric hospitals.
- More than half the children with autism and ASDs (54% autism, 55% ASD) met criteria for serious emotional disturbance.
- Both populations presented with significant impairments in functioning. Almost 60% of children with autism and 46% of children with other ASDs had Global Assessment of Functioning (GAF) scores of 50 and below at intake.

5.7.0 Conclusion: AIMS Data Analysis

Kansas Community Mental Health Centers in 2004 served almost 600 children with an autism spectrum disorder. The preponderance (n=491) had an autism spectrum disorder other than autism. Using the best current epidemiological rate of prevalence, CMHCs served 14.6% of the population estimated to have an ASD. More reliable national data on dually diagnosed children are needed before an accurate approximation of the expected CMHC population can be rendered. CMHCs in the three most populous counties appeared to serve lower percentages of children with ASDs. Diversion from specialty centers, database underreporting, and a better array of school services are possible explanations.

Overall, the children served by CMHCs mirrored the national population: they were 4-5:1 boys, had co-occurring diagnoses of ADHD and disruptive behavioral disorders, and presented with significant impairments in functioning. Over half of both groups met criteria for serious emotional disturbance.³ The largest percentage of children and youth who met criteria for SED status received services other than targeted case management or community psychiatric supportive treatment. The second largest percentage received targeted case management and community psychiatric supportive treatment. Few children in either group received medication management only.

Importantly, the great majority of children served by Kansas community mental health centers lived at home with their families, remained out of hospitals and in school, and did well academically. Children with autism fared somewhat better in this regard than their counterparts with other ASDs, who were more likely to encounter out-of-home placements, school problems, inpatient hospitalizations, and JJA involvement. It is likely that CMHC services provided significant stability for this population at risk for hospitalization and other poor outcomes.

³ This may be an underestimate because of significant missing data.

6.0 KANSAS FINDINGS: COMMUNITY BASED SERVICES AND COMMUNITY DEVELOPMENTAL DISABILITY ORGANIZATION STAFF & DIRECTORS' SURVEY

6.1.1 Purpose

To understand how the CMHC and CDDO systems serve children with autism spectrum disorders and mental health needs, KU staff surveyed Kansas CMHC Community Based Services (CBS) directors and Community Developmental Disability Organization (CDDO) directors. CBS directors requested an email survey. Accordingly, a brief online survey was created. Email invitations and reminders were sent to all CBS and executive directors of CMHCs and to all CDDO directors. Forty-seven respondents completed the survey—22 from Community Mental Health Centers and 25 from Community Developmental Disability Organizations. Response rate was 84%. Responses represented 19 discrete CMHCs and 19 CDDOs. Questions covered a range of topics from subjective perception of service adequacy to specific types of interventions used by individual agencies. In addition to likert scale and multiple choice questions, respondents were given the opportunity to write in narrative comments at different points in the survey. Researchers coded and analyzed these comments qualitatively. Survey results follow.

6.2.0 Respondents and Services Provided

Survey respondents included: 17 CBS directors, 5 CMHC executive directors, 12 CDDO directors, nine CDDO staff members, and four CDDO liaisons. Almost all (91.7%) respondents reported that their agencies provide direct services to children with ASDs; 8.3% of respondents said their agencies were administrators of services only.

Table 13 lists the types of general services provided by responding agency representatives.

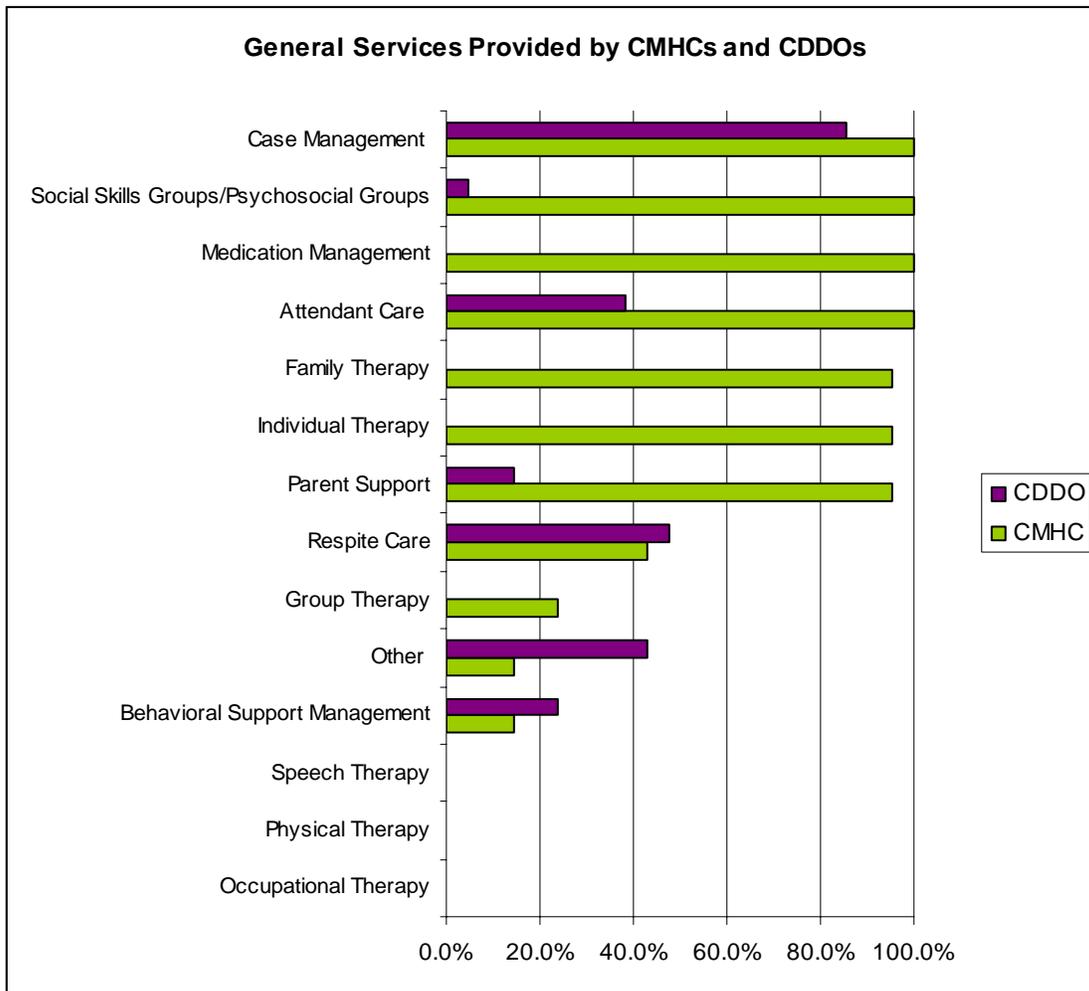
Table 13: Services Provided by CMHCs and CDDOs

Services	% of CMHC Respondents <i>n</i>=21	% of CDDO Respondents <i>n</i>=21
Case Management	100.0	85.7
Attendant Care	100.0	38.1
Medication Management	100.0	0.0
Social Skills Groups/Psychosocial Groups	100.0	4.8
Parent Support	95.2	14.3
Individual Therapy	95.2	0.0
Family Therapy	95.2	0.0
Respite Care	42.9	47.6
Group Therapy	23.8	0.0
Behavioral Support Management	14.3	23.8
Other	14.3	42.9
Occupational Therapy	0.0	0.0
Physical Therapy	0.0	0.0
Speech Therapy	0.0	0.0

As reported by survey respondents, the most widely delivered service in both CMHCs and CDDOs was case management (including targeted case management and community psychiatric support treatment). All responding CMHCs provided case management, as did 85.7% of CDDOs. All responding community mental health centers provided attendant care, medication management, and psycho/social skills groups. A significant percentage of CDDOs appeared to provide respite and attendant care (47.6% and 38.1% respectively), as well as direct family support stipends, supportive home care, dayschool, and assessment services. These account for the 42.9% of “other” services reported by CDDOs. The least provided service was behavioral support management. Respondents may have been lacked clarity about this ambiguous term, which was intended to denote behavioral services other than attendant care. No agencies provide speech therapy, occupational therapy, or physical therapy; these services are provided exclusively by schools.

Figure 6 illustrates the breakdown of services by agency type.

Figure 6: Breakdown of Agency Services as Reported by Survey Respondents



Both CDDO and CMHC systems provide: case management, attendant care, respite care, parent support and behavioral support. CMHCs exclusively provide group, family, and individual therapy; medication management; and most of the attendant care, parent support, and psycho/social skills groups reported. CDDOs provide significant amounts of case management and respite, and exclusively provide family support stipends.

6.2.1 Specific Interventions

Table 14 and Figure 7 display a number of specific interventions aimed at improving the functioning of children with autism spectrum disorders. In addition to these interventions, one respondent noted that in his/her organization, Theraplay, a therapeutic play intervention designed to increase motor skills, communication, and sensory integration was also used to address impairments in social and communication skills.

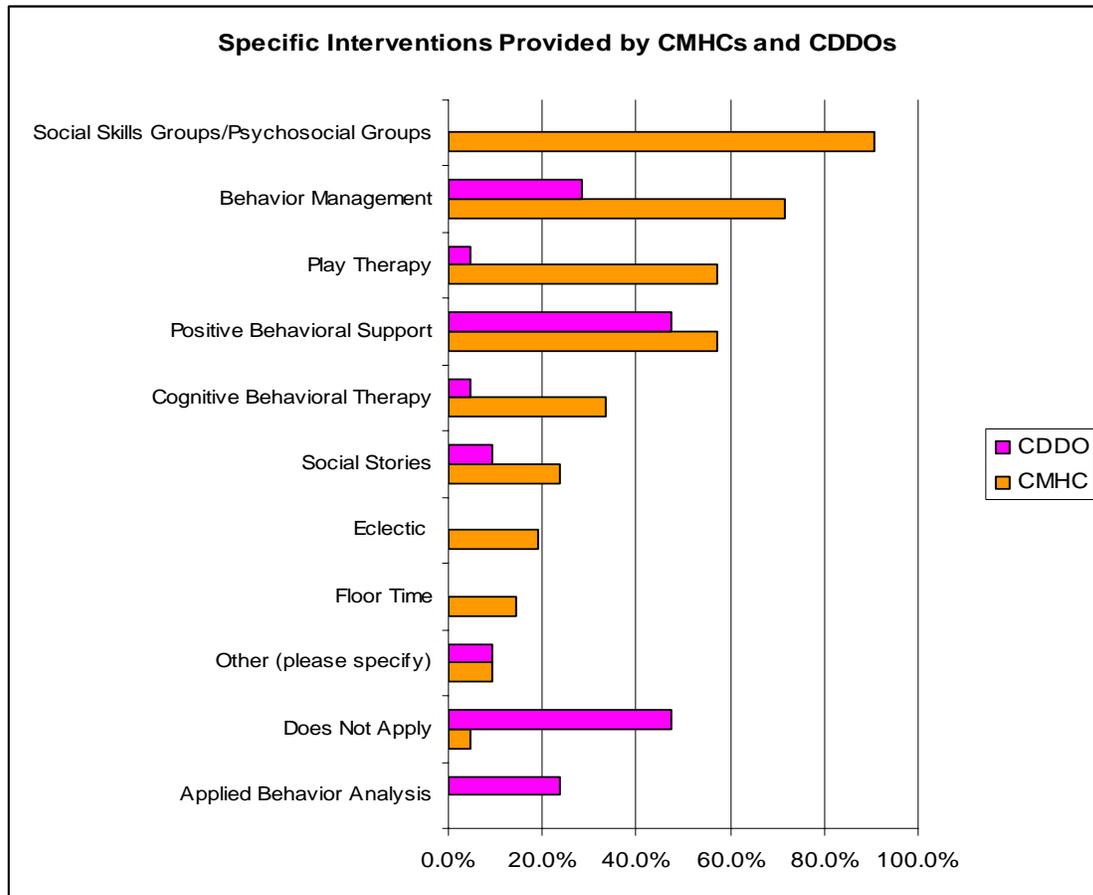
Table 14: Specific Interventions Used in CMHCs and CDDOs

Interventions	% of CMHC Respondents <i>n=21</i>	% of CDDO Respondents <i>n=21</i>
Social Skills Groups/Psychosocial Groups	90.5	0.0
Behavior Management	71.4	28.6
Positive Behavioral Support	57.1	47.6
Play Therapy	57.1	4.8
Cognitive Behavioral Therapy	33.3	4.8
Social Stories	23.8	9.5
Eclectic	19.0	0.0
Floor Time	14.3	0.0
Other (please specify)	9.5	9.5
Does Not Apply	4.8	47.6
Applied Behavior Analysis	0.0	23.8

Almost all CMHC respondents (90.5%) indicated that their agency provides social skills and psychosocial groups to children with autism spectrum disorders. Behavior management, positive behavioral support, play therapy, and cognitive behavioral therapy were the next most prominent interventions. By contrast, in the greatest percentage of CDDOs that employed specific interventions, positive behavioral support and applied behavior analysis were the treatments of choice. Empirical evidence supports the use of applied behavior analysis, social skills and psychosocial groups, positive behavioral support, and cognitive behavioral therapy (with high functioning individuals). There is little empirical support for play therapy, but this modality may have been reported when the intention was to indicate the use of Theraplay, discussed earlier. While Theraplay has no available evaluation studies, it was designed for use with the autism spectrum population. In short, the interventions currently in use in Kansas CDDOs and CMHCs have solid empirical foundations, with the exception of play therapy. Applied behavioral

analysis, which has the strongest research base of any individual approach, should be considered for adjunctive use in CMHCs.

Figure 7: Specific Interventions and their Frequency in CMHCs and CDDOs



6.3.0 Most Common Co-Occurring Diagnoses

Figure 8 and Table 15 display the most frequently occurring comorbid psychiatric diagnoses encountered by CMHC and CDDO directors and staff in the population of children with ASDs. Attention deficit/hyperactivity disorders and disruptive behavior diagnoses predominate. They are closely followed by mood, anxiety, and adjustment disorders. Infrequent are diagnoses of psychotic disorders, tic disorders, or personality disorders. “Other” refers to mental retardation.

These data are both consistent and inconsistent with AIMS data reported earlier in this report. While attention deficit and disruptive behavior disorders were most prevalent among our samples of children with autism (n=107) and other ASDs (n=491), mood and anxiety disorders appeared with less frequency in AIMS than would be expected, given research on co-existing mood disorders in the population and the rates portrayed here. This discrepancy—between the accounts of CBS and CDDO directors and AIMS data—warrants future investigation. Also puzzling is the fact that only CDDOs reported comorbid personality disorders and more CDDOs encountered children with ASDs and

psychotic disorders than did CMHCs. While these disorders are thought to occur infrequently among the ASD population, comorbidity is certainly possible. Further investigation of this discrepancy between CMHC and CDDO diagnostic encounters could be fruitful.

Figure 8: CMHC & CDDO Report of Most Commonly Diagnosed Psychiatric Disorders

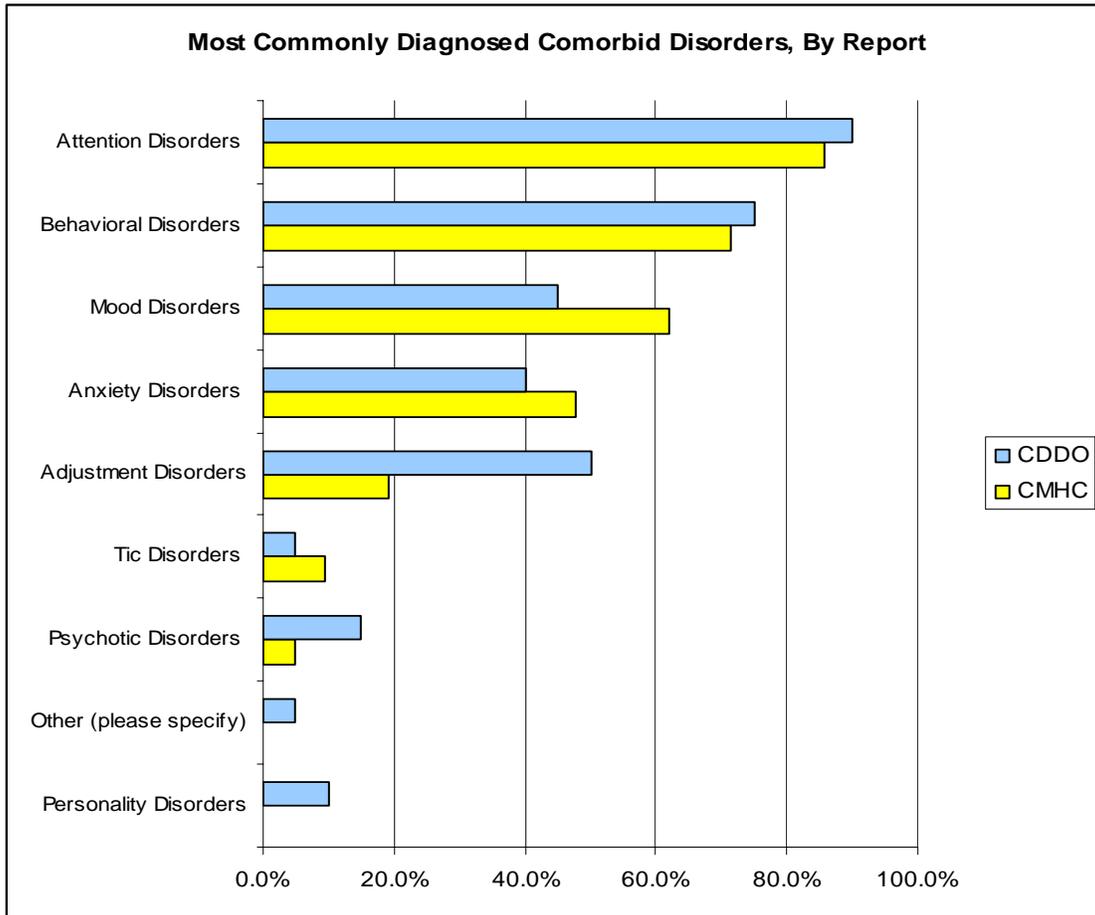


Table 15: Reported Common Comorbid Diagnoses

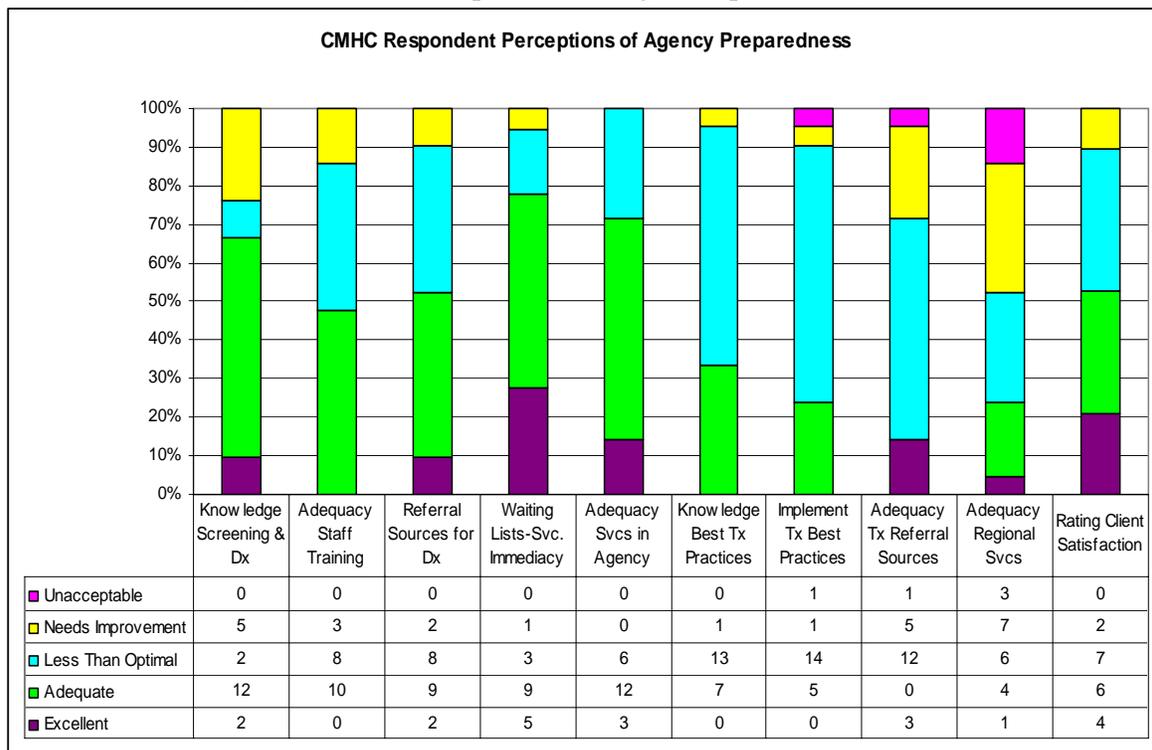
Diagnoses	% of CMHC Respondents <i>n=21</i>	% of CDDO Respondents <i>n=20</i>
Attention Disorders	85.7	90.0
Behavioral Disorders	71.4	75.0
Adjustment Disorders	19.0	50.0
Mood Disorders	61.9	45.0
Anxiety Disorders	47.6	40.0
Psychotic Disorders	4.8	15.0
Personality Disorders	0.0	10.0
Other (please specify)	0.0	5.0
Tic Disorders	9.5	5.0

6.4.0 Subjective Assessment of Agency Preparedness Serving Children with ASDs

CMHC and CDDO directors and staff were asked the following question: “Please rate your agency’s preparedness in serving children diagnosed with a PDD and mental health needs.” Respondents rated their agencies in the following areas: knowledge of screening/diagnosis, adequacy of staff training, referral sources for diagnosis, waiting lists/immediacy of services, adequacy of services in the agency, knowledge of best practices in treatment, implementation of best practices in treatment, adequacy of referral sources for treatment, adequacy of services in the region, and overall client/consumer satisfaction.

Participants scored their agencies’ performance as excellent, adequate, less than optimal, needs improvement, unacceptable, or not applicable (for those agencies that do not deliver services). Figure 9 graphically displays the responses of CMHC respondents. Dark purple, at the bottom of the chart represents the percentage of respondents who judged their agency performance “excellent.” The next (green) portion of the bar chart represents the percentage of respondents who deemed their performance in a given domain “adequate,” and so on. Percentages are cumulative. Thus, 2 CMHC respondents, or 10% of all CMHC respondents, rated their agency as having excellent preparation in the area of “knowledge of screening & diagnosis.” If we combine these responses with those who rated their performance in screening and diagnosis as “adequate,” we see that 66.6% of CMHC respondents felt that knowledge of screening and diagnosis was excellent or adequate.

Figure 9: CMHC Respondent Rating of Preparedness (n=21)

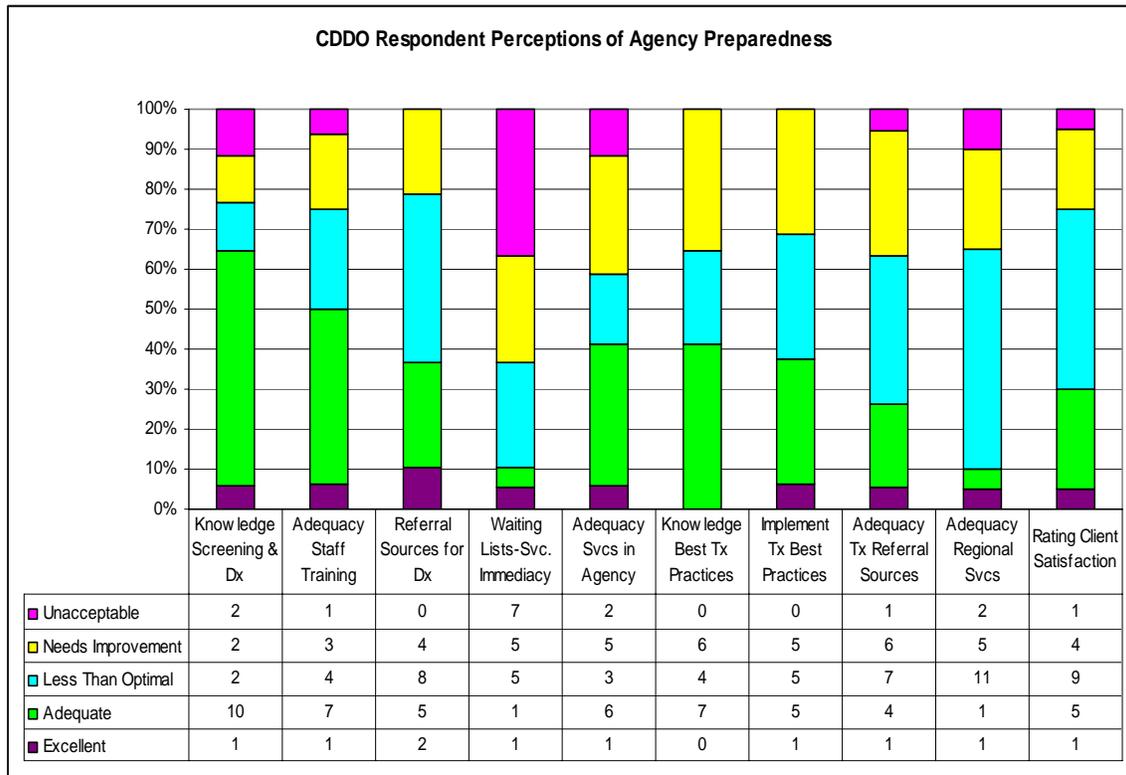


Two thirds of CMHC directors judged their ability to provide timely services excellent or adequate. Generally, agencies felt that they were knowledgeable about diagnosis and screening for children with ASDs, as evidenced by 66.6% rating this area excellent or adequate. Seventy-one percent of CMHCs also felt that they provided adequate services in their respective agencies.

Not surprisingly, questions which exposed regional differences showed the greatest range of responses among CMHCs. There were clearly differences among regional providers in regard to the adequacy of treatment referral sources, as this area was deemed excellent by 3 or 14% of directors, but judged unacceptable by one director and in need of improvement by 23.8% of respondents. Overall, this domain had the highest unsatisfactory rating, with 86% rating it less than optimal, in need of improvement, or unacceptable. Regional service availability was found similarly wanting by 76% of directors. Knowledge and implementation of best practices were deemed unsatisfactory by 66.6% and 76% of respondents, respectively.

Figure 10, below, presents CDDO director and staff responses to this same question.

Figure 10: CDDO Respondent Rating of Preparedness (n=20)



Very interesting differences can be observed between CDDO and CMHC ratings of preparedness in serving children with autism spectrum disorders. The most striking difference, not unexpectedly, is that 89.4% of CDDO respondents judged waiting lists and the timeliness with which they are able to provide services less than optimal, in need of improvement, or unacceptable. Almost 37% found their waiting lists plainly unacceptable. This is in marked contrast to CMHCs, who overwhelmingly (66.6%) rated service immediacy as excellent or adequate. Interestingly, another significant difference between the two systems was in their perception of overall client satisfaction. While slightly more than half (52.6%) CMHC directors judged client satisfaction less than optimal or in the lower ranges, a full 70% of CDDOs felt that clients were less than satisfied. This rating likely reflects, in part, the struggles CDDOs have imposing waiting lists for services.

Nearly two-thirds of responding CDDO staff (64.7%) rated their ability to screen and diagnose children with ASDs excellent or adequate. Staff training, the adequacy of agency services, and knowledge of best practices garnered excellent or adequate ratings by 50%, 41%, and 41% of staff, respectively. Survey participants were less sanguine about implementation of best practices; 62.5% judged their abilities lacking. Like their CMHC counterparts, 90% of CDDO staff rated regional service availability most in need of improvement, followed by 74.6% of respondents who said the pool of providers who could provide treatment was deficient.

Table 16: CMHC and CDDO Combined Perception of Agency Preparedness

	Excellent	Adequate	< Optimal	Needs Imprvt.	Unacceptable	N/A
Knowledge of Screening/Diagnosis	7% (3)	54% (22)	10% (4)	17% (7)	5% (2)	7% (3)
Adequacy of Staff Training	2% (1)	41% (17)	29% (12)	15% (6)	2% (1)	10% (4)
Referral Sources for Diagnosis	10% (4)	34% (14)	39% (16)	15% (6)	0% (0)	2% (1)
Waiting Lists/Immediacy of Services	15% (6)	24% (10)	20% (8)	15% (6)	17% (7)	10% (4)
Adequacy of Services in Agency	10% (4)	44% (18)	22% (9)	12% (5)	5% (2)	7% (3)
Knowledge of Best Practices in Treatment	0% (0)	34% (14)	41% (17)	17% (7)	0% (0)	7% (3)
Implementation of Best Practices in Treatment	2% (1)	24% (10)	46% (19)	15% (6)	2% (1)	10% (4)
Adequacy of Referral Sources for Treatment	10% (4)	10% (4)	46% (19)	27% (11)	5% (2)	2% (1)
Adequacy of Services in Region	5% (2)	12% (5)	41% (17)	29% (12)	12% (5)	0% (0)
Overall Client/Consumer Satisfaction	12% (5)	27% (11)	39% (16)	15% (6)	2% (1)	5% (2)

Taken together, a preponderance of those completing the survey rated the following areas as less than optimal, in need of improvement, or unacceptable:

- knowledge of best practices (58%)
- implementation of best practices (63%)
- referral sources for treatment (78%)
- adequacy of services in the region (82%).

Fifty-eight percent of directors found their agencies wanting in staff knowledge of best practices (less than optimal or in need of improvement). No respondents felt that knowledge of best practices deserved a rating of “excellent,” and only one respondent said their agency performance was excellent in implementing best practices. Rather, nearly two thirds (63%) of survey respondents said implementation of best practices fell into the less than optimal or lower ranges. Moreover, 78% and 82%, respectively, thought that the reservoir of treatment providers and regional resources was less than optimal, needing improvement, or unacceptable. Finally, though not quite as dramatic as the preceding information, more than half of the CMHC and CDDO directors and staff who completed the survey (56%) judged overall consumer satisfaction (of parents and children with ASDs) as less than adequate.

Summary:

Community mental health center and community developmental disability organization directors and staff appear to feel, in general, that their agencies house adequately trained staff and provide a sufficient array of services for children with autism spectrum disorders. They feel especially proficient in their abilities to screen and diagnose ASDs. There are significant differences between CDDO directors and staff and CMHCs in regard to waiting lists. CDDO directors and staff were nearly unanimous in their assessment that waiting lists and delayed services were a significant problem in the DD system. Nearly a third of respondents found waiting lists plainly unacceptable. Comparatively, two thirds of responding CMHC directors approved of their agencies’ timely provision of services. Both system representatives indicated a need for better knowledge and implementation of best practices. Ultimately, in both systems, the biggest barrier to serving children with autism spectrum disorders and their families, apart from waiting lists in the DD system, was a dearth of treatment providers and regional services.

6.5.0 Service Challenges

In addition to the preceding likert scale question, CMHC and CDDO directors responded to two open-ended questions:

“What is the biggest challenge you face in serving (or referring) children with PDDs and co-occurring mental health needs?”

“What one change would best improve service delivery to children with PDDs and mental health needs?”

Provider responses regarding service challenges fell into two main categories: *lack of coordination with other systems and lack of local resources*. In general, providers noted insufficient capacity to serve this population and insufficient clarity about which system should take the lead in providing services to this population—the CDDO or CMHC system.

Service challenges noted by CMHCs included:

1. Lack of coordination between systems/lack of clarity about lead agency
2. Waiting lists (DD waiting lists)
3. Lack of expertise/tools
4. Lack of local resources
5. Discrepancy between population needs and system design of CBS services

Service challenges noted by CDDOs included:

1. Lack of coordination between systems (including schools)/lack of clarity about lead agency
2. Waiting lists
3. Lack of expertise/tools
4. Lack of local resources (especially in rural areas)
5. Lack of funding

Comments from CMHCs targeted long waiting lists for the DD waiver, and noted their mandate to serve children regardless of an available HCBS slot. Similarly, comments from CDDO directors, while occasionally directed at schools, were aimed primarily at lack of services from CMHCs.

Tables 17a and 17b display selected provider survey comments. These comments indicate that there are a number of serious impediments to adequate service delivery. Based on candid provider responses, it would be fair to say that neither the CDDO nor CMHC system feels adequately equipped to meet the needs of this population. Moreover, both systems think the other system should do more.

Table 17a: CBS and CDDO Director Responses: What is Your Biggest Service Delivery Challenge?

CMHC Director Responses	CDDO Director & Staff Responses
Lack of Coordination Between Systems/Lack of Clarity About Lead Agency	
<p>“My understanding is that if the child is PDD, the MR/DD system is to take lead. This does not happen because of a lack of slots for HCBS waiver. We only serve these children when they have a co-occurring disorder but the families often need the services of the CDDO as primary.”</p> <p>“Deciding what is the primary diagnosis. The expectation that we are the primary provider of services as a CMHC.”</p> <p>“Depends on which is primary. If PDD diagnosis is primary, the resources from CDDO are usually very limited unless they’re on the [DD] Waiver. We have a great working relationship with our local providers, but we often find ourselves as the only providers.”</p>	<p>“If the child has been determined to have a developmental disability meeting the State's definition for DD, mental health services beyond medication management are determined not to be beneficial because of cognitive difficulties.”</p> <p>“Mental health are not responsive to their needs; they keep saying it is a DD issue.”</p> <p>“Getting the school systems to appropriately serve these children.”</p>
Waiting Lists	
<p>“Currently there are waiting lists for formal evaluations as well as at the local CDDOs for service delivery. We have parents and schools requesting more services and support for children with these diagnoses.”</p> <p>“Lengthy, lengthy waiting list for kids who qualify for MR/DD services and complete lack of direct services available to the family.”</p> <p>“When referring to the CDDO, being put on very long waiting lists for any services at all.”</p>	<p>“Waiting list for additional services. Families not feeling they're getting adequate support from our local CMHC (no other options available). Foster care parents not receiving adequate training for supporting children with challenging behaviors.”</p>
Lack of expertise/tools	
<p>“We don't always have the expertise that the CDDO's have in working with this population. We have a good relationship with our CDDO and they do serve children, which I understand does not happen in other parts of the state. CDDO's need to have the same requirement as MHC's to serve even without available HCBS slots.”</p> <p>“Adequate diagnostic tools to ascertain clarity of neuro/educ/psych/social concerns and tx.”</p> <p>“Some staff are not as well versed as others in diagnosing and treating these disorders. The functional limitations a child with PDD experiences makes the treatment of co-occurring mental health disorders much more difficult.”</p>	<p>“After referral process is completed, and recommendations are given by specialists, the difficulty is finding local or reasonable distance agencies to provide such supports or being specialized in providing supports to children with PDDs.”</p> <p>“Lack of expertise, experience, and interest to treat children with cognitive deficits.”</p> <p>“Trained staff.”</p>

Table 17b: CBS and CDDO Director Responses: What is Your Biggest Service Delivery Challenge?

CMHC CBS Director Responses	CDDO Director Responses
Lack of resources/funding	
<p>“Lack of resources to refer parents to in the community. Our CDDO offers no services to these children.”</p> <p>“Someone interested in working with this population as a specialty.”</p> <p>“Limited resources for families within our rural/frontier counties.”</p>	<p>“The ability to find service providers with the ability to work with these children. DD pay rates are extremely low, so we have no specialized staff. The mental health facilities do not provide in-home supports or financial stipends for families. We do not provide the in-home supports, but we do fund those services. Also, our waiting list is large for DD services. We do have a behavioral specialist consultant who helps as many families as he can, but his time is limited.”</p> <p>“We serve individuals in rural areas; transportation and support for families is our greatest challenge.”</p>
Discrepancy between population needs and system design of CBS services	
<p>“...Our community based service system for children with severe emotional disturbance (SED) is based on a design of time-limited intensive treatment and support (one-two year maximum) which assumes children will respond to treatment and "graduate" to minimal supportive services, or no longer require services. Children with Autism Spectrum disorders frequently have ongoing intensive service needs which do not fit in this service design. These ongoing service needs are most frequently in the areas of behavior management and social skill building, services which are outside our primary service focus and staff expertise.”</p>	
Lack of funding	
	<p>“Lack of funds to provide adequate services.”</p> <p>“The biggest challenge would be funding. In MR/DD services, funding is not available to provide in-home supports or respite services to new referrals. Unless there is a crisis, individuals must be placed on the statewide waiting list for funding.”</p> <p>“Budgets.”</p> <p>“Unavailability of immediate funding for services.”</p> <p>“Funding.”</p>

6.6.0 Provider Recommendations

In response to another open-ended survey question, “What one change would best improve service delivery to children with PDDs and mental health needs?” respondents answered in the following ways. As above, answers are grouped by themes and responses are selected for representativeness.

CMHC recommendations include:

1. Improve CMHC-CDDO coordination
2. Target services to population
3. Fund DD system and compel it to serve children with ASDs
4. Create diagnostic centers/diagnostic expertise/resource directory
5. Training/education

CDDO recommendations include:

1. Increase funding
2. Coordinate and train other systems/providers
3. More resources (especially rural)
4. Create ASD/PDD Waivers
5. Establish service guidelines

6.6.1 Community Mental Health Center Responses:

1. Improve CMHC-CDDO coordination

- “Improved coordination between CDDOs and CMHCs. Sometimes children with these disorders fall through the cracks. Some PDDs, like autism, do not qualify a child as SED in the MH system, which may limit services that can be accessed.”
- “Better coordination between systems and direct services for kids with MR/DD and their families.”

2. Target services to population

- “Specifically targeted services designed to treat persons with PDD and Asperger's, coupled with sufficient funding to sustain adequate service capacity.”

3. Fund DD system and compel it to serve this population

- “Requiring the CDDO to have the obligation to serve these children, not dependent on an available HCBS slot.”
- “Eliminating the waitlist for MR/DD waiver. Mental health cannot do it all for these kids and we need the services that this waiver would provide.”

- “Properly fund the Developmental Disorders so that their expertise can be utilized and so that long waiting lists do not occur.”
- “That all children in need of resources through the CDDO would...[have services] available. Not on a waiting list. That the CDDO would deliver services not just be a broker.”
- “CDDO to assist with service provisions.”

4. Create diagnostic centers/diagnostic expertise/resource directory

- “Statewide investment in diagnostic center for multi-involved diagnosed children.”
- “Better availability of developmental pediatric services.”

5. Training/education

- “Graduate level course work for students to prepare them better for this population prior to employment.”
- “We do need more training opportunities in collaboration with the CDDOs and more effective and updated intervention.”
- “Training for both service providers and community partners.”
- “Increase awareness of treatment or school based interventions. It is very difficult to assess which diagnosis is primary and maybe that criteria should be changed in order for youth to receive necessary services.”
- “More qualified staff to work with these populations.”
- “These children need specialized services for which the DD community does not have the training.”

6.6.2 Community Developmental Disability Organization Responses :

1. Increase funding

- “More funding would allow us to offer more services and better meet the needs of the families.”
- “Expand expertise of MH professionals to use treatment methodologies/best practices with children with cognitive limitations, or provide an adequate funding stream for the DD system to provide clinical treatment services, since the DD system has the expertise.”
- “Immediate funding.”

- “Adequate funding for necessary supports and services.”
- “For the State of Kansas to realize that the DD community is not capable of serving these children due to limited funding.”

2. More resources (especially rural)

- “Availability of more support agencies/opportunities for services for children & families that reaches out to less urban areas.”
- “Not having to travel 6 hours to get any direct services & supports for assessment, diagnosis, and direct family resources. We provide the best supports we can with our limited resources.”
- “An increase in satellite mental health offices, better qualified individuals at the centers, a decrease in the state wide waiting lists.”
- “More outreach from the few resource centers available in our state.”

3. Coordinate and train other systems/providers

- “Agencies working together.”
- “Joint initiatives.”
- “Training regular education teachers in positive behavioral support techniques.”
- “Joint training as to needs and trends in treatment. Joint expectations for partnerships in services. Joint training on Positive Behavioral Supports and structuring environments for success versus consequences based approach.”
- “Educational services/specialized teaching and educators knowledgeable about children with Autism/PDD.”
- “We also need to increase education of our school system in working with this population.”
- “Parent training.”

4. Create ASD/PDD Waivers

- “I believe the best change would be to offer a waiver which strictly provides services to individuals with PDD. This waiver should incorporate services such as in-home supports, respite care, case management, behavioral analysis, support groups, and so on.”

- “Funding of the early intervention waiver when the child is diagnosed.”
- “We need to improve and expand the DD waiver.”

5. Establish service guidelines

- “We would like to see clear guidelines so children with PDDs either fall under the SED Waiver or under the Autism umbrella.”
- “Better understanding of the rules for each population and how they are similar and how they are different.”

6.7.0 Conclusion: Provider Survey

Seventeen community behavioral services (CBS) directors, five community mental health center executive directors, and 25 community developmental disability organization directors and staff members responded to an online survey about the challenges they face in providing services to children with autism spectrum disorders and co-occurring mental health needs.

Both groups expressed considerable frustration with a general lack of services for this population and felt the other system could be doing more. There was agreement among directors from both systems that the top priority is to better fund the CDDO system. Directors on both sides felt that the DD system was more appropriately equipped to handle the long-term needs of this population. CDDO directors expressed frustration with budgetary constraints and the DD system’s concomitant incapacity to provide direct services. CMHC directors echoed this sentiment, with one main difference: Many CMHCs appeared to believe that responsibility for this population was chiefly that of the CDDO. This sentiment was expressed less on the CDDO side.

While lack of funding was perhaps the biggest identified impediment, both sides also reported related barriers to services, including: 1) long waiting lists and a dearth of competent local providers; 2) among staff, a lack of training, expertise, knowledge of best practices, or desire to work with this population; and 3) a significant lack of coordination with other systems, primarily CDDOs and CMHCs, but also the school system.

Survey respondents offered the following recommendations to mitigate these barriers: 1) increasing funding to the DD system; 2) clarifying the roles of each agency with regard to dually diagnosed (and other) children with ASDs, perhaps through service manuals; 3) creating specific ASD waivers to serve all children with an ASD from birth to 22; 4) providing local training and joint training with other systems and providers; and 5) creating regional diagnostic centers.

7.0 KANSAS FINDINGS: PARENT FOCUS GROUPS & INTERVIEWS

To learn more about parent experiences identifying the need for services, obtaining services, and financing services, four regional parent focus groups and ten parent phone interviews were conducted between February and June, 2005. In all, 29 parents from all regions of the state participated. Additionally, parents who attended focus groups or who had email access completed a brief questionnaire (Appendix D). The following section discusses findings from questionnaires, focus groups, and interviews. Parents' and children's names have been changed; in some cases, children's ages and genders have been changed to protect confidentiality.

7.1.1 Themes from Parent Focus Groups, Interviews, and Questionnaires

7.1.2 *Most helpful services, general*

Kansas City specialty providers. Parents from all regions of the state reported that they received the most helpful services from Kansas City specialty providers, including the University of Kansas Medical Center, the Autism Asperger Resource Center (AARC), and Children's Mercy Hospital.

So my only other thing that I wanted to say that AARC has been very supportive ...*They were there for me in the beginning and I don't know what I'd do without them.* (NE Region)

Local specialty providers. A small number of local providers (e.g. the one developmental pediatrician in the Wichita area) also generally received high praise (with a few detractors).

Select schools. Parents expressed deep gratitude for a handful of schools, school districts, teachers, specialized programs, and principals with sufficiently trained personnel and a commitment to serve their children. However, parents also unanimously reported difficulty with one or another school at some point in their child's school experience.

The district actually—*it makes me so sad when I hear other parents say what a hard time they had getting help because we, I really feel that we have been very blessed.* (NE Region)

Regional hospitals/residential schools/organizations. Some parents found regional hospitals (Prairie View, University of Kansas Medical Center), organizations (Rainbows, Inc.) and residential schools (Lake Mary School) helpful for information, diagnosis, and crisis stabilization.

The most informational help was from Prairie View, from the people that...had the school there for kids with Asperger's. That was the most helpful because we sat down with the teacher, spent an hour. We observed the classroom...KU was helpful because it confirmed that. They gave a good long report on the things that would be most helpful for him. And so they came up with a lot. The problem was implementing that. (Western Region)

Waiver services. Once families were able to qualify for either DD or SED waiver services, they found CMHCs and CDDOs helpful. Parents were most appreciative of family support stipends. They also expressed gratitude for respite and attendant care but expressed frustration with the lack of trained paraprofessionals to provide these services. Additionally, these services were not available in all parts of the state. More than one parent asked researchers for help finding appropriate service providers.

It made a huge difference once we had respite. (NE Region)

Right now we have gotten funding for Home Based Community Services (I think that's it) and I'm looking for someone to be Becky's provider. If you know anyone interested, please feel free to give my email address...I think it pays around 10.00 an hour – it's set by the State. That's a service position I'm trying to get filled for Becky. (Grandparent email: Southeast Region, names changed)

Case management/medication management. In general, parents found case management and medication management useful. However, some parents complained of high case manager turnover and lack of autism spectrum-specific training among child psychiatrists.

My daughter gets along real well with her case manager. I wish she could have more hours with her, just see her instead of her therapist. The therapist is a nice lady, but she can't get her to open up the same way. (Western Region)

We've gone through 4 different case managers since we've been working with the CDDO. (NE Region)

I'm sorry, but I think I know more about his diagnosis than the psychiatrist at the center. It's not their fault; I just wish they'd be honest about what they don't know and refer us somewhere else. (Western Region)

Heartspring School. One parent received services from Heartspring School in the 1980s and found it enormously helpful for her child. Other parents expressed their disappointment that such a well-known special needs school serves few Kansas families due to high costs, but predominantly serves families from other states.

7.1.3 Identifying the need for services

Diagnostic process. Parents almost universally expressed frustration with the diagnostic process. Many encountered long waits (6 months to 13 years) for a diagnosis from a qualified provider; were disappointed when Infant and Toddler Services (ITS) and other early intervention programs failed to send them to a specialist sooner; struggled to get their pediatricians to give a diagnosis; and felt hindered by bureaucratic and school delays in procuring requisite functional evaluations and appropriate special education services. Parents described the diagnosis as the “key” to services, but narrated many situations in which it was necessary to enlist help from advocates to obtain promised services.

[Someone] told us to go to a doctor at Children’s Mercy. *And so that’s what we did, [but there was] a six month backlog. It was like four months before they even called us for our telephone interview. And then a week before our appointment, they called and said [the doctor] had to cancel it. And I was like, “What!” And they got us in in another month. So it was like eight months later we finally, finally saw the doctor and filled out all this paperwork and stuff and sent it in. And she was with him like 20 minutes and she said, “Yeah. Okay. Well, I see PDD-NOS.” And we’re like, “What’s that?” There it was, pervasive developmental disorder not otherwise specified. And she talked all about the autism umbrella and because the first thing you think of, the first thing everybody in my family thought of—I didn’t even tell them it was autism for like two years—was Rainman. And oh, my God. Your child is autistic? They’re never going to be able to function. So I didn’t tell people for a long time, a long, long time. And I did a lot of crying. And so this was right after his fourth birthday we got the official diagnosis.* (NE Region)

I like the mission of Infant and Toddler Services. *I think it’s important. I think you will find that everything that’s happening is because of the F word, which is funding (and training). But I, too, felt horribly betrayed by Infant and Toddler Services. When I had this diagnosis, someone comes in and I’m still without a compass and a map. We did massive internet searches...But we are in grief and loss. We are absolutely devastated, immobilized by the terror of not being able to reach this child. And to have Infant and Toddler Services never give us information regarding even an eval, when we had already started with them, because they would have had to pay for it...* (NE Region)

And then the IEP, we just had a meeting this morning. *The people from AARC, once we commissioned them about three weeks ago, things started happening again. But when it’s only us as parents, even though my husband and I are knowledgeable people, not much happened.* (NE Region)

But the most frustrating thing that I have to tell you is that I am 100% certain that they [the school's early intervention program] knew that we were dealing with an autism spectrum disorder long before we did. And we had a right to know, and the way the laws are, it stinks. Someone needs to change that. Those people should be able to tell you, boy we're seeing some autistic behaviors here. Have you looked into this? They would kind of go in a round about way. They knew I wasn't going to sue the district. I worked for the district. But if someone would have said, "Gee, have you looked into Asperger's syndrome?" we would have known a full year before we did. (NE Region)

In answer to a questionnaire query, "Who or what was most helpful in the beginning?" parents told us about certain providers who had been especially helpful. Others responded: "No one," "the Internet," "books," and "intestinal fortitude."

Dual diagnoses. Parents of children with behavioral disorders often received delayed ASD diagnoses, usually after an extended series of trial and error diagnoses. Attention deficit hyperactivity disorder was the disorder most mistakenly diagnosed before a specialist made an ASD diagnosis. (It co-exists in some cases). Moreover, some parents experienced new needs for services as their children reached adolescence and began to have behavioral problems in school and elsewhere. Many parents found medication helpful for their adolescents, but for some, it meant more trial and error to find the right combination of medication.

I mean...my son was a problem since age 4. He had been diagnosed with ADHD, like everybody. Just at 13, or 12 1/2-- it was like a year ago-- my son got this diagnosis. It's not like he didn't always have it, the disorder, he just didn't have the diagnosis. (NE Region)

[Our son] was 13 when we started this, about junior high. And it was really, that was the first time that we got a diagnosis. [Other than mental retardation and ADD when he was five.] He was in Prairie View for about ten days and they gave us the PDD diagnosis. (Western Region)

And I don't know how you all feel about that, but my son does take a medication for moods and of course stimulants because he does have ADHD with the Asperger's. But I found when the stimulants are increased and at a level where he needs it for focus, etc. the moods get worse, the agitation, because stimulants make the mood disorder worse. And then there we go again. (NE Region)

7.1.4 Obtaining services

Parents who attended focus groups or gave phone interviews described a number of service barriers, both to CMHCs and CDDOs, but also to other systems. To remain faithful to the content of those communications, service barriers other than for CDDO or CMHC services will be reported in this section.

General satisfaction with CDDO & CMHC systems. With few exceptions, parents criticized both mental health and developmental disability systems. Parents of children who qualified for SED or DD waiver services were more satisfied with CMHCs or CDDOs, respectively, than were other parents in our sample. However, waiver usage among the parent sample was low, and all parents in our sample encountered barriers to diagnosis, treatment, and financial assistance.

Overall, parents had more experience with the CDDOs and were more satisfied with CDDOs than with CMHCs. This was true even of parents who were on the waiting list for the DD waiver. Parents who qualified for the SED waiver were the exception.

Long waiting lists. Parents described lengthy waiting periods for evaluations and diagnoses in the beginning, and for suitable services as their child encountered new challenges at each developmental stage. Most encountered waits (6 months to 13 years) for a diagnosis from a sufficiently qualified practitioner, felt utterly alone in the process, and got the most help from other parents or from the internet. They expressed a unanimous sense of urgency and “lost opportunities” for improvements in functioning.

At 3 yrs. old, he was referred by his pediatrician to the university psychology department, where a “team” of specialists tested our son over the period of 5-6 hours. We were told that he had autism and referred back to our local community. We had spent over a year trying to get a diagnosis prior to this referral. (NE Region)

We’re getting the diagnosis at two and three when we’re totally isolated. We don’t have that support system. (NE Region)

When she was first diagnosed we found little or no help. Because of her behaviors she was confined to Larned State Hospital for several months. This we did not find to be helpful. (Western Region)

Lack of services. Many parents expressed frustration with the lack of services available to them or the confusing and sometimes lengthy process of qualifying for services. Regional variation in service availability was marked. Parents in all regions of the state expressed disappointment and frank confusion about the paucity of services in their regions. However, parents in the western and southeastern regions of the state appeared most underprovided. A parent from the southeast region of the state, where there is no organized advocacy presence, said she has spent years trying to get help with her son’s

behavioral and toileting problems. Although she received some DD waiver services, these offered little in the way of changing her son's everyday experience:

We have [the CDDO contractor] out here. We have them. We don't do a whole lot with them. *Attendant care, that's all. And actually, my mom and my aunt is able to do that. Just mainly in-home visits once every 2-3 months. At this point, I'd be willing to get on a waiting list just to get some help...I just think there needs to be more services offered for SE. I mean, there's nothing down here right now. (Southeast Region)*

Two parents in western Kansas reported that their CDDO does not provide services to children. (This CDDO provides family support stipends; the parents did not report receiving such a stipend.) When they sought services through the CMHC, they were told that the staff had insufficient training to deal with their child, who had previously been hospitalized in Larned and Prairie View. Eventually, these parents gave up custody of their child to access an appropriate residential treatment school, where their child did well.

And so then, when he was home and we could see that we weren't going to get the services that he needed through the center again, *we then again tried to see what we could do with the MR/DD waiver, local with our CDDO. Again, we ran into, "He's not 18 yet. We can't work with him until he turns 18." So we had no services available other than [the CMHC]... Finally the administrator, I met with him one afternoon and he said, "We don't deal with kids like Travis. We can't help him." And so when you hear that from the only game in town that we can't do anything for him. We don't work with...It got to the place then where the only alternative we had then was back at Lake Mary. But in order for that to happen, we had to then relinquish custody again and move him back into the SRS system in order for him to qualify to be able to go back. And that was really frustrating. (Western Region, names changed)*

Lack of information. In some cases, services were available but parents didn't know about them. A mother in south central Kansas discusses the day she learned that her child might qualify for respite services:

Because I went, "What? We can get help? What?" *I remember Martha coming to a meeting and she's like, "Yeah, I took a nap today." And I'm like, "Well, how did you take a nap with your son there?" And she said, "Oh, my respite service came over." And I'm like, "What? What's that? You took a nap? David, did you hear that? She took a nap!" (South Central Region, names changed)*

Other parents, particularly low-income parents, lacked even basic information about qualifying for medical cards or waivers. Many parents asked researchers how they might qualify for services. There is clearly a gap in information, particularly in areas of the state

which lack the organized presence of advocacy groups like Families Together, the Autism Society of America, or Keys for Networking.

Service refusals. Parents of children with high or low functioning *autism*, in particular, were frustrated by the few CDDO or CMHC services for which they qualified. Most parents of children with autism were able to receive services only through the CDDO, with the exception of medication management, which they accessed through the CMHCs. However, they sometimes faced up to a three-year wait for DD services.

Parents of children with severe autism and self-harming behaviors felt keenly abandoned when they were both placed on waiting lists for DD services and refused services through the mental health system. One parent related an experience in which he sought treatment through both systems but was denied.

This was years ago; the HCBS (DD) waiver had a waiting list. *I called [the mental health center] and I said what about the SED waiver? We have children that are self-injurious. They're banging their heads against the wall. They're becoming aggressive. What are we doing? And I said how many children with autism are getting covered? None. None. And I said that's discriminatory. It's not an either or. You can have autism and still have a coexisting. These children have anxieties. They have depression. I mean they've got ADHD. We have a plethora of things. I mean we're like a mutt.* (NE Region)

On the other end of the spectrum, parents of children with high functioning autism and no mental retardation were turned away from CDDOs because their children's IQs were too high.

I, for one, went to [the CDDO] in 2002 and was turned down *because their IQs are too high. Too high functioning IQ. But these kids still can't function in the world.* (NE Region)

Both parents in the above quotes noted that things have changed somewhat since they first sought services. After intervention from the Autism Asperger Resource Center, the CDDO noted in the above quotation had just come to re-evaluate the two children in question.

Parents of children with an *ASD diagnosis and a co-morbid psychiatric diagnosis* were more likely to access services through the CMHCs than parents of children with autism. One parent, who was very pleased with the medication management he received through the CMHC had strong feelings about CMHCs taking the lead with the dually diagnosed population:

...If a kid has a dual diagnosis, the mental health centers are the most appropriate place for treatment. *At least there I'm dealing with people who have an education and some training. They have effective treatments there. My son sees a psychiatrist at the center who provides meds...* (NE Region)

Some parents of *dually diagnosed* children received little from their CMHC and eventually got services from hospitals and private practitioners. Several expressed the sentiment that if you have a crisis, you had better “schedule an appointment” with the CMHC. One parent describes the experience of a close friend with the local CMHC:

They cannot get another appointment when they’re having major problems with their child. *Oppositional behavior, you know...I guess they’re going to have to wait until he does something truly heinous, or violent... (NE Region)*

Lack of training/expertise. From pediatricians who minimized parents’ concerns about their non-verbal children, to teachers with no special education training, to underpaid case managers and underprepared therapists—parents reported that they encountered little professional proficiency in recognizing and working with symptoms of autism spectrum disorders.

Parents complained that with the exception of a few well-trained medical specialists and special education teachers, few professionals had much expertise or training in this area. In general, many parents felt that they had to become experts, mobilize their resources, and train their providers—all while dealing with their own grief, their children’s difficult daily behavioral problems, financial and marital stress, sibling problems, and unresponsive school systems.

People aren’t trained. *You’re training your respite providers. You’re training everyone that walks in your door. There is something horribly wrong. We need a tiered behavior aide paraprofessional training program that would be a pool that could be pulled from for schools when we need behavioral paras, that could be pulled from for residential and community-based programs, residential sites. (NE Region)*

So we made an appointment with a neurologist through KU, who was very good. *I mean she, within two minutes, said, “You need to have confidence in your child’s treatment.” And I said, “That’s exactly right. I have no confidence that this guy knows that he’s doing.” And so that was very good. And then we did change our course of action, but at that point I needed to say, “I mean I cannot go back and be a teacher and be a parent and be a specialist and be his OT and be his speech path[ologist]. And, by the way, become a neurosurgeon at the same time.” I mean it just wasn’t going to happen. (SE Region)*

Lack of coordination. Overall, parents expressed a high level of frustration with the lack of coordination between service systems and a general lack of guidance from any particular system. Parents resorted to coordinating their own treatment teams and “forcing” schools, CMHCs, and other groups to work together.

It's been my experience that there's a great divide between the DD side and the mental health system in this state. *I wish the coordination between the CMHC and the CDDO was better...I sat down with the liaison and basically forced them to coordinate the services better. It seemed so forced, and it just doesn't make sense. I'd say there's a turf issue. I don't know what the problem is; maybe the DD side is fearful that they'll lose their funding, but these kids aren't going anywhere. They're going to need services from both sides for a long time.* (NE Region)

Uneven experiences with schools. A recurrent theme in the stories of parents was the need to move several times to find a school district with enough trained personnel to serve their children adequately. In more than one case, parents relocated based entirely on the reputation of the school district. However, some noted that this was a problem because school districts soon became overloaded and then had to restrict services. Lawrence was given as an example of a once exemplary school district which no longer provides many services to children with autism spectrum disorders.

Parents expressed deep gratitude to the few teachers and providers who helped them. Overall, though, even improvements in functioning were described as short-lived. Families reached tenuous plateaus when all was well, but they feared the loss of a particular teacher, paraprofessional, or the transition to another school or developmental phase with all its attendant challenges and consequent uncertainties.

Donna has had a couple of good teachers. *I mean, we have to say: they were outstanding. And when she had those teachers, she did very well. When she didn't have those teachers, it would blow up.* (Western Region)

Moreover, statewide policy changes—such as the elimination of classroom size restrictions—had deleterious effects on children with ASDs, who suddenly went from classrooms with six other children, for example, to classrooms of 14 children with behavior disorders. Parents expressed fear that their children would be victimized by children with severe behavioral disorders. Some parents quit their jobs in order to be with their children in school.

7.1.5 Financing services

Financial sacrifices. The financial burden of an ASD is substantial for parents of all incomes. As mentioned above, it was not uncommon for parents in the sample to move to other cities in an effort to procure better services for their children. Many spouses quit their jobs or took demotions to take care of their child or children with an ASD. One mother has been her child's full-time paraprofessional at school for the last six years.

Single parents quit their jobs in order to stay home with their children who were receiving few services from the schools. Middle and upper income parents paid significant out-of-pocket expenses to procure diagnoses, behavioral consultations,

trainings for themselves, or other services. Some parents receiving Medicaid conveyed frustration that the options mentioned above—procuring trainings or consultation—were closed to them. They could not pursue alternative treatments in the same manner as parents with higher incomes and had to rely on the expertise of those providers willing to accept Medicaid reimbursement.

Two middle-income parents relinquished custody of their child to SRS in order to get needed residential services.

In instances in which the child did not qualify for waiver services and insurance would not pay, parents accrued sizeable medical debt.

The whole way we have bought and paid for consultants with Visa cards and any means that we could get. We are on the [MR/DD] waiver. That's \$150 a month that we get to help out with all this. Visa cards, that's our real waiver. (Western Region)

So I called my case manager at ITS [Infant and Toddler Services] and said, "It's come to my attention that perhaps he should go to KU." Because my husband and I are like, "Well, what do we do? What do we do?" And so she said, "Well, maybe you could do that. Is your insurance company going to cover it?" And I said, "I don't know. Well, how much is it?" She goes, "Well, it's like \$1500." Now, of course here we are now, three years later we've spent almost \$60,000, but at the time, "What? \$1500?" (NE Region)

7.2.0 Parent Recommendations

1. Provide services in underserved areas.

There has to be a system available to where you can afford the services that your child needs without either going bankrupt or having to give your child over to the state. (Western Region)

2. Provide better training for teachers, paraprofessionals, case managers, respite providers, attendant care providers, physicians, and therapists.

Parents recommended maintaining a pool of trained behavioral paraprofessionals and aides to work as paraprofessionals in schools, or as respite and attendant care providers in the home. They also wanted the state to maintain regulatory standards for professional behavior (e.g. limited time off for personal crises), as some parents had difficulty with the providers they were authorized to hire with waiver monies. Parents also wished the state would utilize university resources more, so they didn't feel that they were footing the bill to train professionals. About their out-of-pocket expenses for training providers, one parent commented:

Or you could have the university train a whole class. *Why are we spending the money to train the state's resources?* (NE Region)

3. Allow more flexibility in MR/DD waiver funding.

I would gladly trade my respite funding for funding that I could use for speech, OT, materials, additional therapies, etc. *I would also be happy to submit requests for approval of services or materials before funds were disbursed, along with receipts after, in order to insure that money is being spent in a responsible way. Another way that funding would be more useful to me, personally, is if I could use it to employ someone to take over some of my paraprofessional duties at school for part of the day. But the regulations right now don't allow you to use any of your respite hours during school hours - the assumption being, obviously, that the school is taking care of everything adequately.* (South Central Region)

4. Provide a list of service providers to parents of newly diagnosed children.

...It's such a crushing blow to receive an ASD diagnosis for a child and there's so much to learn, it would be fantastic if there was more useful advice routinely handed out along with the diagnosis—beyond, “See a geneticist and get an EEG.” *If there was a list of statewide practitioners experienced in autism (psychologists, pediatricians, speech therapists, consultants, etc.) and current therapies with proven track records (ABA, TEACH, PECS, Floor time, etc.), including information on how to get started, it would be a god-send for most of us, and a lot more efficient than word of mouth from other parents in the trenches. Kids who have to rely on public school services alone are frequently not being well-served. In order to make the progress they are capable of, they need additional services.* (South Central Region)

5. Offer incentives to professionals who want to specialize in neurodevelopmental disorders, e.g. in-state tuition for non-residents, free tuition for residents.

6. Re-assess insurance policies, as the state is forced to absorb the costs of treatment when insurance companies deny treatment on the basis of developmental disorder. Enforce the Kansas Mental Parity Act.

And they had three physicians, their panel that they hired, they were all there, and the physician said to Blue Cross and Blue Shield, your policy is outdated. It's antiquated, because they wouldn't even cover speech therapy because they said he's not two standard deviations below normal. And so they said we don't care what our physicians say, we're not covering this. So we went to the state of Kansas and filed a complaint. We won the complaint...then the state of Kansas said, “You have to cover this. This boy has autism. He falls under the Kansas Mental Parity Act.” They said, “Okay.” Let's see, we submitted about \$30,000 of claims and they paid \$6,000 and they denied every

one past that because it's not covered. "We don't cover autism." Now they're going all the way back. Then they said, "Well, he's not two standard deviations below normal." And we're like, "Oh, my God. Are you kidding me? You have to cover this."

- 7. Engage in long-term planning to facilitate successful transitions for a growing group of children with ASDs who will reach legal age and require adult supportive services.**
- 8. Create a specific division to provide leadership with autism spectrum disorders.**

And we don't really truly feel like there is any leadership at the state level that clearly owns us. And we're Jewish, so I can say I feel like a wandering Jew. We are the unwanted disability. (NE Region)

8.0 POLICY IMPLICATIONS/RECOMMENDATIONS

1. **Consider passage of an early childhood autism waiver.** At the least, an early childhood waiver for children aged 0-5 could mitigate delays in diagnosis and treatment. Research has shown that early, intensive intervention can alter substantially the outcomes of children with autism spectrum disorders. Conversely, lack of early and intensive intervention can compound the severity of disability and the cost of services over the child's life span.
2. **Consider passage of a comprehensive autism waiver.** A comprehensive waiver for individuals aged 0-22, including a Katie Beckett option for higher income parents, could potentially expand services to children who need them. Wisconsin recently restructured its long-term children's care plan in order to increase local decision making, reduce fragmented funding, develop consistent eligibility, assure consistency between counties, address service gaps, and eliminate waiting lists. Wisconsin currently offers four HCBS waivers: Brain Injury, Children's Long-Term Support, Community Integration and Placement, and a Community Options Program waiver. Under the general umbrella of Children's Long Term Care, Wisconsin administers four separate HCBS waivers for children: a physical disability waiver, an SED waiver, a DD waiver, and an autism waiver. To be eligible, a child must meet:
 - Level of care criteria which is determined by an online functional screen;
 - For state matched slots, disability determination by Social Security;
 - Financial eligibility;
 - Additional criteria for Intensive In-Home Autism Treatment slot.
 - Additional criteria for an In-Home Autism Treatment slot are: verified diagnosis of an ASD; residence in Wisconsin for 6 months; one year commitment from family to participate in services; child under 8 years of age; child has not previously received 3 years of in-home autism-specific services; there is a qualified provider ready to begin providing services when a slot becomes available.
 - Children in intensive in-home slots receive one-on-one behavioral treatment only. No other non-treatment services are authorized for children in the intensive phase of the program.
 - Children enrolled in on-going autism slots may pursue behavioral treatment or receive other supportive services including adaptive aids, communication aids, consumer education and training, consumer and family-directed supports, counseling and therapeutic resources, daily living skills training, day services, home modifications, personal emergency response system, respite care, specialized medical and therapeutic supplies, specialized transportation, support and service coordination, and supportive home care.

The Wisconsin autism waiver contains costs by:

- Limiting available autism waiver slots to 1,000;
- Limiting services to children who have not previously received, from any payment source, three years of intensive service;
- Allowing 35 hours per week of face-to-face service for up to three years for children 8 and under; and
- Providing a capped annual stipend (\$10,000) for services to children 8-22.

A report of the Wisconsin Governor's Task Force on Autism may be accessed online at: <http://www.dhfs.state.wi.us/BDDS/clts/autism/finalrep.pdf>. The report discusses changes to the waiver system as well as taskforce and insurance issues germane to Kansas.

3. **Support the creation of regional diagnostic centers and/or telemedicine initiatives.** The Kansas Governor's Commission on autism has recommended the establishment of regional diagnostic centers to aid in the timely diagnosis of a population for whom early intervention is key. Additionally, with funding from the National Institute of Health, researchers at the University of California-Davis are studying the viability of telehealth solutions to service barriers in rural areas. Researchers will develop guidelines for implementing technologies such as clinical telemedicine, distance learning, and information distribution so that empirically based practices can be implemented where service gaps exist. Once the guidelines are complete, the State of Kansas may wish to review them and consider implementing telemedicine initiatives that fit the state's unique needs.
4. **Increase workforce capacity in CMHCs, CDDOs, and schools by training staff in currently accepted best practices. Establish an infrastructure of ongoing supervision and consultation to maintain provider capacity.** Workforce issues are a top priority. Local specialty providers (such as the Autism Asperger Resource Center, the University of Kansas Medical Center, Children's Mercy hospital, and local specialists in agencies like Family Service and Guidance) may be utilized for trainings and ongoing consultation/supervision purposes. Additionally, national leaders in autism research provide local introductory trainings for mental health clinicians, health professionals, and teachers and paraprofessionals through New England Educational Institute (NEEI) workshops and conferences. NEEI generally has at least two local trainings per year. Longer trainings could be arranged for lead clinicians and educators, who could then train others in their respective agencies.

5. **Create a specialized division within SRS, like Massachusetts' Autism Division.** Appointing visible leaders at the state level would signal a commitment to serve this population and allay the feelings of some parents that they are entirely alone. Additionally, a specialized division could reduce fragmented funding, develop consistent eligibility, promote consistency between counties, address service gaps, and eliminate waiting lists.
6. **Establish an interagency coordinating committee** made up of SRS-HCP staff, CMHCs, CDDOs, and schools. Lack of coordination across systems has been recognized by upper level administrators, parents, and providers alike. An interagency coordinating committee could provide recommendations for achieving a more seamless system of care for children with ASDs and mental health needs. One early task could be the establishment of some general service guidelines for this population. (See next point).
7. **Develop service protocols delineating primary agency responsibility in the case of dual diagnosis.** A key finding of this study is that no one system—CDDO or CMHC— is best suited to serve consumers' needs. Both systems are needed to serve the unique needs of this population, needs which vary widely on a case-by-case basis. However, in the interest of better service provision, CDDO and CMHC directors requested guidance on this matter.

Three factors make the establishment of general service protocols difficult: 1) the idiopathic nature of autism spectrum disorders; 2) the expansion of both ends of the spectrum to include high functioning children with autism (and no comorbid cognitive deficits) and lower functioning children with other ASDs (and some cognitive deficits); and 3) the idiosyncratic nature of co-occurring psychiatric disorders in children with ASDs. The heterogeneity of the population has been a major obstacle to progress in autism science, and continues to be a major obstacle to determining which service system should take the lead in serving this population.

In other words, autism and autism spectrum disorders share common hallmarks like difficulties initiating and sustaining social interactions; impaired communication skills; and restricted, repetitive patterns of behavior. However, these hallmarks vary considerably in severity. There is no one clear etiology upon which to base mandatory insurance coverage, for example, and we lack reliable information on the true prevalence of certain comorbid psychiatric diagnoses among children with autism spectrum disorders.

Moreover, there is a professional consensus among autism researchers and clinicians that the spectrum is wider than once thought. At present, some children with high functioning autism have little cognitive impairment. Thus, service eligibility thresholds based on cognitive impairments could deny this subset of children services through the DD system. Also in recent years, the lower functioning end of the Asperger's/PDD-NOS spectrum has been recognized.

While these children may have high verbal IQ's, they may also have significant discrepancies between verbal and performance IQ scores. Thus, functional ability, rather than IQ alone, should be the threshold criterion on which qualifying or disqualifying decisions are based. Additionally, some children with low functioning autism and self-harming behaviors may need more than medication management through the CMHC system.

In summary, we cannot automatically assume that children with autism should be served through the DD system, and children with other ASDs through the CMHCs. Children's individual clinical needs must be evaluated, with the recognition that these needs may change over the course of their lives. For example, a child who did not display behavioral problems when young may begin to display them in adolescence.

Designing service protocols is thus a task best left to an interagency coordinating committee, such as the one recommended above. This task could be undertaken with the consultation of clinical specialists at the University of Kansas Medical Center, Children's Mercy, or the Autism Asperger Resource Center. Diagnostic algorithms and critical pathways, two solutions offered by managed care companies, are discouraged. Diagnostic algorithms can become overly restrictive and limit rather than expand services to the population in question.

8. **Draft state-wide service provider list for parents of children just diagnosed.** While parents of children with other disorders like Down Syndrome often receive an information packet and guidance when their child is initially diagnosed, parents of children with autism spectrum disorders said that they received very little guidance in the way of qualified providers or suggestions for treatment. A state-wide service provider manual, updated regularly, could be maintained on the SRS website. One possibility would be to contract with the Beach Center or the Autism Society of America and have them update and maintain a service provider list online. The Beach Center published a manual of service guidelines for parents in 2003. It is available at:
<http://www.beachcenter.org/Books%5CFullPublications%5CPDF%5CServicesForChildrenandYouth.pdf>.
9. **Work with Kansas Insurance Department and the Kansas Insurance Commissioner to assess fidelity to Kansas Mental Health Parity Act.** Parents with insurance reported that their insurance companies routinely denied claims for coverage if their child did not have a primary medical diagnosis (e.g. seizure disorder) in addition to an autism spectrum diagnosis. In one focus group, parents reported that after taking their insurance company to court and the state ruling in their favor, the insurance company in question still refused payment. Insurance denials shift the burden of treatment to the state; as such, they could be investigated to determine whether denials are inappropriate and a breach of the Kansas Mental Health Parity Act of 2001.

10. **Improve rural service availability** by offering incentives for specialty providers and by re-assessing service coverage of administrative-only CDDOs. Additionally, regional collaboratives between CDDOs and CMHCs could address service gaps in the western and southeastern regions of the state.
11. **Increase pool of specialists** by offering incentives to resident and non-resident psychiatrists, medical professionals willing to remain in state and specialize in neurodevelopmental disorders.
12. **Change AIMS data recording procedures for CMHCs** so they record all ASD diagnoses—primary and secondary. This will permit a more accurate estimate of the ASD population served by Kansas CMHCs.
13. **Allow funding discretion for parents** so they can fund what they most need, with accountability measures built in. In the absence of a larger system overhaul, DD waiver stipends could be made more flexible so that parents could purchase needed services currently not allowed on the waiver. Other states have done this (e.g. Wisconsin), with the caveat that non-empirically based treatments would not be reimbursed by the waiver plans.
14. **Study more optimal service delivery models for children with ASDs and mental health needs.** This initial study of service challenges to children with ASDs and mental health needs has been descriptive and partial. For year two, researchers propose to answer the following questions:
 - How can we gain the clearest picture of the duration and types of services, across systems, currently provided to children and youth with an ASD and co-occurring mental health needs? For example, how extensive is waiver usage? Which children, in which diagnostic categories, are being served by the SED waiver and the DD waiver? What types of services are being provided under each waiver? What are typical utilization patterns? What are typical utilization patterns of children with Medicaid vs. private insurance? Could these service patterns be optimized?
 - Based on results of CDDO and CMHC director surveys, and parent focus groups, which portions of the state are most in need of training and staff development? What promising consultation/supervision models exist?
 - Which training and service needs identified through the service provider survey and the parent focus groups are most urgent? What barriers to implementation exist and how might they be mitigated?
 - What are barriers to changes in state funding options exist? How might they be mitigated?
 - How could greater collaboration between CDDO and CMHC systems be fostered and institutionalized? How could greater collaboration between DD, mental health, and school systems be fostered?

REFERENCES

American Academy of Pediatrics. (2001). The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 107, 1221-1226.

American Psychiatric Association 2000. (DSM-IV-TR) Diagnostic and statistical manual of mental disorders, 4th edition, text revision. Washington, DC: American Psychiatric Press, Inc.

Barfield, S., Holmes, C., Barket, A., Chamberlain, R. & Corrigan, S. (2005). Home and community-based services: Mental health waiver for children and youth with severe emotional disturbance. University of Kansas, School of Social Welfare.

Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M. & Decoufle, P. (2001). Prevalence of autism in a United States population: The Brick Township, New Jersey investigation. *Pediatrics*, 108, 5, 1155-1161.

Boyd, E.H. (2005). Mercury toxicity: Genetic susceptibility and synergistic effects. *Medical Veritas*, 2, 535-542.

Bradley, E., Summers, J., Wood, H. & Bryson, S. (2004). Comparing rates of psychiatric and behavior disorders in adolescents and young adults with severe intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*, 34(2): 151-161.

Bryson, S., Rogers, S., & Fombonne, E. (2003). Autism spectrum disorders: Early detection, intervention, education, and psychopharmacological management. *Canadian Journal of Psychiatry*, 48, 506-525.

California Department of Developmental Services (2002). Autistic spectrum disorders: Best practice guidelines for screening, diagnosis, and assessment. California. Retrieved 8/11/05 from <http://www.ddhealthinfo.org>.

Campell, M., Schopler, E., Cueva, J. & Hallin, A. (1996). A treatment of autistic disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 134-143.

Centers for Disease Control (2006). Mental health in the United States: Parental report of diagnosed autism in children aged 4-17 years. Retrieved 5/25/06 from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5517a3.htm>.

Center Autism Developmental Disability Epidemiology (CADDE). Johns Hopkins University Bloomberg School of Public Health. Autism Fact Sheet. Retrieved 5/25/06 from <http://www.jhsph.edu/cadde/Facts/autism.html>.

Clark, T., Feehan, C., Tinline, C., Vostanis, P. (1999). Autistic symptoms in children with attention deficit-hyperactivity disorder. *European Child and Adolescent Psychiatry*, 8, 50-55.

Charman, T. & Baird, G. (2002). Practitioner review: diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology and Psychiatry*, 43, 289-305.

Committee on Children with Disabilities. (2001). Technical report: The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 107, 1221-1226.

Costello, E.J., Foley, D., & Angold, A. (2006). 10-year research update review: The epidemiology of child and adolescent psychiatric disorders: II. Developmental epidemiology. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45,1, 8-25.

Croen, L.A., Grether, J.L., Hoogstrate, J., & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders*, 32, 207-215.

Dawson, G. & Osterling, J. (1997). Early intervention in autism. In M. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 307-326). Baltimore, MD: Brookes Publishing.

Department of Developmental Services. (1999) Changes in the population of persons with autism and pervasive developmental disorders in California's developmental services system: 1987 through 1998. Report to the legislature. Retrieved 8/11/05 from http://www.dds.cahwnet.gov/Autism/pdf/Autism_Report_1999.pdf.

Fombonne, E. (2003). The prevalence of autism. *Journal of the American Medical Association*, 289, 87-89.

Fombonne, E. & Chakrabarti, S. (2001). No evidence for a new variant of measles, mumps, and rubella-induced autism. *Pediatrics*, 108 (58).

Geier, M. & Geier, D. (2003). Thimerosal in childhood vaccines, neurodevelopment disorders, and heart disease in the United States. *Journal of American Physicians and Surgeons* 8(1), 6-11.

Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders*, 32(4): 299-306.

Jacobson, J., Mulick, J. & Green, G. (1998). Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behavioral Interventions*, 13, 201-226.

Jacobson, J. & Mulick, J. (2000). System and cost research issues in treatments for people with autistic disorders. *Journal of Autism and Developmental Disorders*, 30, 585-593.

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

Jensen, V., Larrieu, J., Mack, K. (1997). Differential diagnosis between attention deficit/hyperactivity disorder and pervasive developmental disorder not otherwise specified. *Clinical Pediatrics*, 36, 555-561.

Kraus, M.W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty care medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation*, 41, 5, 329-339.

Lord, C. (1995). Follow-up of two-year-olds referred for possible autism. *Journal of Child Psychology and Psychiatry*, 1995, 36, 1365-1382.

Lord, C., Schopler, E., & Revicki, D. (1982). Sex differences in autism. *Journal of Autism and Developmental Disorders*, 12, 317-330.

Madsen, K.M., Hviid, A., & Vestergaard, M. (2003). A population-based study of measles, mumps, and rubella vaccination and autism. *New England Journal of Medicine*, 347,1477-1482.

Mandell, D., Cao, J., Ittenbach, R., & Pinto-Martin, J. (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*, 36 (4), 475-485.

Mandell, D., Novak, M. & Zubritsky, C. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116, 1480-1486.

Mandell, D., Listerud, J., Levy, S., & Pinto-Martin, J. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1447-1453.

Mark, T., Buck, J., Dilonardo, J., Coffey, R., & Chalk., M. (2003). Medicaid expenditures on behavioral health care. *Psychiatric Services*, 54, 188-194.

Mars, A., Maulk, J. & Dowrick, P. (1998). Symptoms of pervasive developmental disorders as observed in prediagnostic home videos of infants and toddlers. *Pediatrics*, 132, 500-504.

Mele, N.C. & Flowers, J.S. (2000). Medicaid managed care and children with special health care needs: A case study analysis of demonstration waivers in three states. *Journal of Pediatric Nursing*, 15, 2, 63-72.

M.I.N.D. Institute, University of California, Davis. (2002). Report to the legislature on the principal findings from the epidemiology of autism in California: A comprehensive pilot study. Davis, CA. October 17, 2002.

National Institute of Mental Health. Autism Spectrum Disorders (Pervasive Developmental Disorders). Retrieved 8/11/05 from <http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>

National Research Council. (2001). *Educating children with autism*. Washington, DC: National Academy Press.

New York Department of Health Early Intervention Program. (1999). Clinical practice guideline: The guideline technical report—Autism/pervasive developmental disorders, assessment, and intervention for young children (age 0-3 years). Albany, NY: Department of Health.

Perry, A. & Condillac, R.,(2003). Evidence-based practices for children and adolescents with autism spectrum disorders: Review of the literature and practice guide. Children's Mental Health Ontario. Toronto: Ontario.

Pichichero, M.E., Cernichiari, E., Lopreiato, J. & Treanor, J. (2002). Mercury concentrations and metabolism in infants receiving vaccines containing thimerosal: A descriptive study. *Lancet*, 360, 1737-1741.

Rapin, J. Current concepts: autism. *New England Journal of Medicine*, 197, 97-104.

Ronder, R.W., Kastner, T., Parker, S.J. & Walsh, K. (1999). Serving people with developmental disabilities in Medicaid managed care. *Managed Care Quarterly*, 7, 2, 23-30.

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

Semansky, R.M. & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *The Journal of Behavioral Health Services and Research*, 31, 3, 334-342.

Shattuck, P. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in U.S. special education. *Pediatrics*, 117(4), 1028-1437.

Stratton, K., Gable, A. & McCormick, M.C. (2001). Immunization safety review committee: Thimerosal-containing vaccines and neurodevelopmental disorders. Washington, D.C.: National Academies, Institutes of Medicine.

Taylor, B., Miller, E., Lingam, R., Andrews, N., Simmons, A. & Stowe, J. (2002). Measles, mumps, and rubella vaccination and bowel problems or developmental regression in children with autism: population study. *British Journal of Medicine*, 324, 393-396.

Tidmarsh, L. & Volkmar, F. (2003). Diagnosis and epidemiology of autism spectrum disorders. *Canadian Journal of Psychiatry*, 48 (8), 517-525.

U.S. Census Bureau, Population Division. (2005). Annual estimates of the population by selected age groups and sex for counties in Kansas: April 1, 2000-July 1, 2004. Release Date: August 11, 2005. Retrieved 2/12/06 from <http://www.census.gov/popest/estimates.php>.

U.S. Department of Education. (1997). Individuals with disabilities education act amendment of 1997, P.L. (pp. 105-117). Washington, D.C.: Author.

U.S. Department of Education. (1999). To assure the free appropriate public education of all children with disabilities. Twenty-first annual report to congress on the implementation of the individuals with disabilities education act. Retrieved 8/11/05 from <http://www.ed.gov/about/reports/annual/osep/1999/execsum.pdf>.

U.S. Department of Education. (2001). To assure the free appropriate public education of all children with disabilities. Twenty-third annual report to congress on the implementation of the individuals with disabilities education act. Retrieved 8/11/05 from <http://www.ed.gov/about/reports/annual/osep/2001/toc-execsum.pdf>.

U.S. Department of Education. (2004). Individuals with disabilities education improvement act of 2004. Retrieved 6/22/06 from http://frwebgate.access.gpo.gov/cgibin/getdoc.cgi?dbname=108_cong_public_laws&docid=f:publ446.108.

Walter, U., Davis, S. & Petr, C. (2005). Admission of young children to state hospitals in the Kansas mental health system. University of Kansas, School of Social Welfare.

Wisconsin Governor's Task Force on Autism. (2004). Report of the governor's task force on autism. Retrieved online 5/25/06 from <http://www.dhfs.state.wi.us/BDDS/clts/autism/finalrep.pdf>.

Volkmar, F. (1997). *Childhood disintegrative disorder*. Washington, D.C.: American Psychiatric Press.

Volkmar, F., Cook, E., Pomeroy, J., Realmuto, G. & Tanguay, P. (1999). Practice parameters for the assessment and treatment of children, adolescents and adults with autism and other pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38 (suppl), 32-54.

Volkmar, F., Lord, C., Bailey, A., Schultz, R. & Klin, A. (2004). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry*, 45 (1), 135-170.

Volkmar, F., Szatmari, P. & Sparrow, S.S. (1993). Sex differences in pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 21, 109-130.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C. & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association*, 289, 49-55.

Yoshida, Y. & Uchiyama, T. (2004). The clinical necessity for assessing attention deficit/hyperactivity disorder (AD/HD) symptoms in children with high-functioning pervasive developmental disorder (PDD). *European Child and Adolescent Psychiatry*, 13: 307-314.

APPENDICES

APPENDIX A: SAMPLE FOCUS GROUP FLIER



Seeking Family Feedback

on

Services for Children with Autistic Spectrum Disorders & Mental Health Needs

The KU School of Social Welfare is currently conducting a study of the mental health needs of children with Autism Spectrum Disorders. The study examines how families find services for their children and how well these services meet their children's needs.

Staff members of the KU School of Social Welfare are now in the process of recruiting focus group participants. We are seeking parents and caregivers of children with mental health needs and a diagnosis of Asperger's Syndrome, Autism, Pervasive Developmental Disorder-NOS, Rett Syndrome, or Childhood Disintegrative Disorder. We are talking with families across the state to see what is going well and what might need improvement with regard to the types of services that families are receiving, how quickly they received the services, how families afford services, etc. Feedback from parents and caregivers across the state will be included in a final report, but no individual person will be identified. We hope that family participation in focus groups will help improve services for children in Kansas.

We are particularly interested in hearing from parents who have received waiver services or whose sole means of financing services is Medicaid.

However, if you are the caregiver of a child with an Autism Spectrum Disorder and mental health needs and you have sought or received services through a Community Mental Health Center, a Community Developmental Disability Organization, or through other providers, we welcome your participation.

How to participate:

If you would like to attend a focus group, please contact Stephanie Bryson at (785) 864-3730, sbryson@ku.edu. **The Southeast Region focus group will take place Thursday, April 20, 2006 from 7-9 p.m. at Southeast Kansas Mental Health Center, 402 South Kansas, Chanute, KS 66720.** Please contact Stephanie by **April 19** if you would like to participate. If you know a family that might be interested, please pass this flyer on to them. Thanks for your help!

APPENDIX B: INFORMED CONSENT FORM, PARENT FOCUS GROUPS

Service Challenges for Children with Autism Spectrum Disorders and Mental Health Needs

INTRODUCTION

The School for Social Welfare at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with the University of Kansas.

PURPOSE OF THE STUDY

The purpose of the project is to clarify the nature of service delivery to families of children with coexisting mental health needs and a ASD diagnosis, to evaluate the potential for collaboration between the CMHC and CDDO systems, and to assess the need for innovative funding streams to facilitate the delivery of timely, appropriate services.

PROCEDURES

You have been asked to participate in a focus group on the experiences of parents who are seeking mental health services for their child with a Pervasive Developmental Disorder and mental health needs. Focus groups will last approximately 1-2 hours and will consist of questions about your experience with the diagnostic process, the treatment process, barriers you have encountered, and changes you would recommend given your experiences with mental health and community disability providers. We are asking your permission to audiotape these sessions. Tapes will only be heard by a paid transcriptionist. At no time will any of your identifying information be disclosed. You are also being asked to complete a brief questionnaire prior to the focus group.

RISKS

Talking about your experiences seeking services for your child with a pervasive developmental disorder can be emotionally taxing. We intentionally chose the focus group format to provide support to parents talking about these potentially painful issues. Our hope is that the format will attenuate risks to participants by bringing together those with common experiences. If during the course of the focus group or after the focus group you find yourself in need of debriefing, project staff are all licensed mental health clinicians. We can assist you with immediate debriefing. Additionally, at each focus group, project staff will be prepared to hand out a list of area mental health clinicians who specialize in supportive family counseling. We will also provide information on

local support and advocacy groups for parents of children with Autism and Asperger's Syndrome.

BENEFITS

Parent focus groups can provide invaluable, unique information to state-level administrators. Participation in this study will benefit other families of children with PDDs and mental health needs by allowing us to make recommendations based on parent reports about areas in which service delivery and coordination needs greater development.

PAYMENT TO PARTICIPANTS

Participants will not receive remuneration for their participation in this study.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. To report narrative information from focus groups, researchers will use a pseudonym instead of your name. At no time will your identifying information be shared in any way. Your quotes may be shared, but they will be linked only to a pseudonym or a descriptor such as "a parent from Western Kansas."

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Stephanie Bryson, 1545 Lilac Lane, School for Social Welfare, Lawrence, KS 66045. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email dhann@ku.edu or mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Type/Print Participant's Name	Date
Participant's Signature	

Researcher Contact Information

Susan Corrigan, Ph.D.
Principal Investigator
School of Social Welfare
Twente Hall
University of Kansas
Lawrence, KS 66045
(785) 830-9241

Stephanie Bryson, MSW
Project Coordinator
School of Social Welfare
Twente Hall
University of Kansas
Lawrence, KS 66045
(785) 864-3730

APPENDIX C: PARENT FOCUS GROUP QUESTIONS

Assessment/Diagnosis

How was your child diagnosed?

Tell us about the process.

What most worried you in the beginning?

Who or what was most helpful in the beginning?

What was most frustrating?

What do you wish had been different in the beginning?

Services/Interventions

What kinds of services/programs/interventions has your child received?

Where did you go to access these services/programs/interventions?

Costs/Finances

How were these services financed?

What have been the costs to your family?

Best Practices and Changes to the System

What has helped most?

What have been biggest obstacles you've faced?

If you could change three things about the way Autism/Asperger treatment has been provided, what would you change?

If you could make one recommendation to the state, what would it be?

APPENDIX D: PARENT FOCUS GROUP QUESTIONNAIRE

Parent Services Questionnaire

Thank you for your willingness to share your experiences with us. Please answer the following questions to the best of your ability. This information is confidential; we will not share any individual answers.

1. How was your child (or children) diagnosed with an Autism Spectrum Disorder?

2. What is the current age and most recent diagnosis given to your child (or children)? Please include all mental health diagnoses.

3. Who or what was most helpful in the beginning?

4. What was most frustrating/frightening in the beginning?

5. Have you had challenges or problems getting services for your child/family? If yes, please describe the problem and whether/if it was fixed.

6. What kinds of services has your family and child received? *(Check all that apply.)* If you wish, tell us who provided the service.

- Attendant Care
- Behavior Management
- Family Therapy
- Group Therapy
- Individual Therapy
- Medication Management
- Parent Support
- Physical Therapy
- Respite Care
- Social Skills Groups
- Special Education Services
- Speech Therapy
- Occupational Therapy
- Other (please specify)_____

7. What service was most difficult to access? Please look at the services in Question 6 and circle the service that was most difficult to access.

8. What specific interventions has your child (or children) received? *(Check all that apply.)*

- Applied Behavior Analysis
- Positive Behavioral Support
- Cognitive Behavioral Therapy
- Dietary/Holistic
- Floor Time
- Play Therapy
- Social Stories
- Social Skills Groups
- Other (please specify)_____

9. Have you sought services for your child(ren) with an ASD and mental health needs from the following? (Check all that apply.)

- Agency (e.g. Autism/Asperger Resource Center)(please specify: _____)
- Community Developmental Disability Organization
- Community Mental Health Center
- Pediatrician
- Private Practitioner (please specify) _____
- School
- Other (please specify) - _____

If you sought or received services from a CDDO, please answer the following question. If not, please skip to question 11.

10. Overall, how satisfied are you with the services your child/family has received from the CDDO? (Check one.)

- Very Satisfied
- Satisfied
- Dissatisfied
- Very Dissatisfied

Please explain.

If you sought or received services at a Community Mental Health Center, please answer the following question.

11. Overall, how satisfied are you with the services your child/family has received from the Community Mental Health Center? (Check one.)

- Very Satisfied
- Satisfied
- Dissatisfied
- Very Dissatisfied

Please explain.

Thank you for your time!

APPENDIX E: PROVIDER SURVEY CONSENT FORM

Services Challenges for Children with Pervasive Developmental Disorder and Mental Health Needs

INTRODUCTION

The School for Social Welfare at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with the University of Kansas.

PURPOSE OF THE STUDY

Like many other states, Kansas struggles to serve children with mental health needs and a co-occurring Pervasive Developmental Disorder (PDD). In most communities, services to children with the most prevalent Pervasive Developmental Disorders—Autism, Asperger’s Syndrome, and PDD NOS—are delivered through two distinct systems: Community Developmental Disability Organizations (CDDOs) and Community Mental Health Centers (CMHCs). Funding is a challenge if a child does not qualify for assistance through the MR/DD Waiver on the disability side or the SED Waiver on the mental health side. Preliminary research indicates that parents of children with Pervasive Developmental Disorders encounter barriers to a range of needed services, including social and cognitive interventions; case management; special education; speech and physical therapies; and psychiatric evaluation and medication monitoring.

The purpose of the project is to clarify the nature of service delivery to families of children with coexisting mental health needs and a PDD diagnosis, to evaluate the potential for collaboration between the CMHC and CDDO systems, and to assess the need for innovative funding streams to facilitate the delivery of timely, appropriate services.

PROCEDURES

You have been asked to participate in a survey on CMHC or CDDO system service delivery to the population of children identified as having a Pervasive Developmental Disorder and mental health needs. Surveys will take approximately 20 minutes to complete and will be emailed to you. Surveys will ask questions about general service delivery to this population and detailed questions about particular interventions and diagnostic assessment tools used by clinicians or staff in your organization.

RISKS

We do not anticipate any risks or personnel reprisals from participating in this study.

BENEFITS

Better understanding current patterns of service delivery and funding will enable SRS to provide appropriate services, through appropriate channels, to the population of children with PDD and mental health needs. We anticipate that the provider survey will greatly enrich our current understanding of this phenomenon.

PAYMENT TO PARTICIPANTS

Participants will not receive remuneration for their participation in this study.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any way with the information collected about you or with the research findings from this study. Specific CMHCs and CDDOs will be identified in final reports so that resources may be better allocated to those organizations in need of human or financial resources and so that best practices may be identified and replicated.

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose information collected about you, in writing, at any time, by sending your written request to: Stephanie Bryson, 1545 Lilac Lane, School for Social Welfare, Lawrence, KS 66045. If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email dhann@ku.edu or mdenning@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Type/Print Participant's Name	Date
Participant's Signature	

Researcher Contact Information

Susan Corrigan, Ph.D.
Principal Investigator
School of Social Welfare
Twente Hall
University of Kansas
Lawrence, KS 66045
(785) 830-9241

Stephanie Bryson, MSW
Project Coordinator
School of Social Welfare
Twente Hall
University of Kansas
Lawrence, KS 66045
(785) 864-3730

APPENDIX F: PROVIDER SURVEY

Text of Director/Provider Survey

1. Please select the type of agency in which you work.

- Community Mental Health Center
- Community Developmental Disability Organization
- Other (please specify)

2. Does your agency serve children with Pervasive Developmental Disorders?

- Yes
- No

3. What is your job title?

- Director, CMHC
- Clinical Director, CMHC
- CBS Director, CMHC
- Clinical staff, CMHC
- Director, CDDO
- Staff, CDDO
- Liaison, CDDO

4. What general services to you provide to children with PDDs and mental health needs? (Check all that apply).

- Individual Therapy
- Family Therapy
- Medication Management
- Physical Therapy
- Behavioral Support Management
- Speech Therapy
- Case Management
- Respite Care
- Attendant Care
- Social Skills Groups
- Occupational Therapy
- Parent Support
- Group Therapy
- Other (please specify)

5. More specifically, what interventions do you use with children who have PDD diagnoses and mental health needs? (Check all that apply.)

- Floor time
- Eclectic
- Cognitive Behavioral Therapy

- Play Therapy
- Social Stories
- Social Skills Groups
- Applied Behavior Analysis
- Play Therapy
- Positive Behavioral Support
- Other (please specify)

6. Please rate your agency's preparedness in serving children diagnosed with a PDD and mental health needs. (Please select one answer from the following options: Excellent, Adequate, Less Than Optimal, Needs Improvement, or Unacceptable.)

- Knowledge of Screening/Diagnosis
- Adequacy of Staff Training
- Referral Sources for Diagnosis
- Waiting Lists/Immediacy of Services
- Adequacy of Services in Agency
- Knowledge of Best Practices in Treatment
- Implementation of Best Practices in Treatment
- Adequacy of Referral Sources for Treatment
- Adequacy of Services in Region
- Overall Client/Consumer Satisfaction

7. What are the most common co-occurring mental health diagnoses among children with PDDs who present at your agency?

- Anxiety Disorders (e.g. OCD)
- Mood Disorders (e.g. Depression)
- Tic Disorders (e.g. Tourette's Syndrome)
- Behavioral Disorders (e.g. ODD)
- Attention Disorders (e.g. ADD)
- Adjustment Disorders (e.g. Mood and Conduct)
- Personality Disorders (e.g. Schizoid Personality Disorder)
- Psychotic Disorders (e.g. Schizophrenia)
- Other (please specify)

8. If you refer children with PDDs or children in need of diagnostic assessment, to whom do you routinely refer? (E.g. Private practitioners, local agencies, specialty centers, etc.)

9. What is the biggest challenge you face in serving children with PDDs and co-occurring mental health needs?

10. Please tell us anything you think we should know about service delivery to children with PDDs and mental health needs.

11. What one thing would best improve service delivery to children with PDDs and mental health needs?

APPENDIX G: LIST OF BEST PRACTICE RECOMMENDATIONS⁴

<i>Age</i>	<i>Screening for Autism spectrum disorders</i>
0 to 5	All professionals responsible for the care of children perform routine developmental surveillance to identify children with atypical development.
0 to 5	All professionals involved in the care of young children are aware of developmental indicators of ASD.
0 to 5	Specific screening for ASD occurs for all children at 18 and/or 24 months of age.
0 to 5	Parents' concerns about their child's development and behaviors are elicited at every health care provider contact, including well- and ill-child visits.
0 to 5	A regional interagency training and information sharing process is in place to assure early identification of persons with ASD.
0 to 5	Healthcare professionals stay up-to-date on best practice guidelines and related research.
0 to 5	Specific screening between 18 and 24 months for ASD includes the Modified Checklist for Autism in Toddlers (M-CHAT) or the Pervasive Developmental Disorder Screening Test-II (PDDST II) or other approved instrument.
0 to 5	Primary care providers have access to an up-to-date resource directory that facilitates the referral process of children and adolescents to a clinical team that specializes in diagnosing ASD.
0 to 5	Within the constraints of confidentiality, efficient sharing of information among clinicians assures timely referral and more complete evaluation of children for concerns regarding ASD.

⁴ Reproduced in its entirety from Appendix N, California Department of Developmental Services (2002). *Autistic spectrum disorders: Best practice guidelines for screening, diagnosis, and assessment*. California. Retrieved 8/11/05 from <http://www.ddhealthinfo.org>.

<i>Age</i>	<i>Diagnostic Evaluation</i>
0 to 5	The diagnosis of ASD should be made as soon as possible to facilitate intervention and initiate family counseling.
0 to 5	All clinical team members are familiar with and are able to recognize the child's developmental level and behaviors that correspond to the diagnostic criteria for ASD in young children.
0 to 5	Because symptoms change over time, a young child with an early diagnosis of ASD should be re-examined at least annually to confirm the diagnosis and plan treatment.
0 to 5	To enable intervention as soon as possible, the diagnostic evaluation is efficiently organized and coordinated.
0 to 5	The diagnostic evaluation includes examination of multiple domains of functioning to: differentiate ASD from other conditions, and provide a complete profile of the individual to allow for comprehensive intervention planning and service initiation.
0 to 5	Planning for diagnostic evaluation before meeting with the child and family includes: identifying and reviewing all sources of relevant background information, selection of tests including alternative test procedures and identifying opportunities for informal observation that can supplement formal assessment procedures.
0 to 5	An interdisciplinary team is the preferred method for conducting a comprehensive diagnostic evaluation. In the absence of the interdisciplinary team, a single clinician with specialist training and experience in evaluating ASD in young children can make a diagnosis. The primary health care provider is involved with other professionals in the diagnosis and treatment of a child with ASD, and assists and coordinates specialty care and referrals.
0 to 5	Informed clinical judgment is maintained through periodic training that includes case review, peer review of individual cases, and discussion of published literature.
0 to 5	When clinically indicated, observations of a child in various settings and at different times increases the validity of information obtained and assists in diagnosis, case management and intervention.
0 to 5	The evaluative process begins with a review of all sources of relevant background information. Attempts should be made to gather as much of this information as possible before the meeting with the child and family.

0 to 5	Diagnostic accuracy improves when the diagnostic team uses formal diagnostic tools, clinical experience and clinical judgment in diagnosing children suspected of ASD.
0 to 5	A comprehensive medical assessment including health history, physical examination and developmental/neurological examination is performed as part of the diagnostic evaluation.
0 to 5	All children as part of their developmental assessment are screened for vision and hearing with referral to specialists as appropriate.
0 to 5	Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of ASD.
0 to 5	Evaluation of cognitive functioning in both verbal and nonverbal domains is a necessary component of the complete diagnostic profile of the child. Developmental levels and/or informal measures are used when formal measures are inappropriate.
0 to 5	Domains of adaptive function are evaluated for all children, as they are pivotal in diagnosing ASD and/or coexisting mental retardation.
Age	<i>Assessment for Intervention Planning</i>
0 to 5	Ongoing assessment of a child's behavior and developmental profile is maintained in order to reformulate assessment conclusions and plan appropriate intervention.
0 to 5	The involvement of parents is essential in the assessment process as they are most knowledgeable regarding the child.
0 to 5	Cultural and family values are considered throughout the assessment process, as they will guide team recommendations and intervention planning.
0 to 5	The setting in which the child is evaluated, i.e., office, home or childcare facility, is carefully chosen to obtain representative information regarding development and behavior.
0 to 5	Although all domains must be explored for each child, the interdisciplinary team tailors in-depth assessments to the unique needs of each child and his or her family.

<i>Age</i>	<i>Formulation, Presentation and Documentation of Findings</i>
0 to 5	The final diagnostic formulation derives from using clinical judgment to integrate clinical data with DSM-IV/ICD-9 diagnostic criteria.
0 to 5	Presentation of the diagnosis to family members is accomplished by those clinicians or team members best able to communicate a comprehensive understanding of the child and support parents during the discussion.
0 to 5	Written reports document diagnostic conclusions keyed to specific DSM-IV criteria. Evaluation and assessment reports are comprehensible to parents and providers and contain practical recommendations for the next phase in the process.
<i>Age</i>	<i>Issues and Concepts in Referral, Diagnostic Evaluation and Assessment</i>
6+	Referring parties are provided with detailed information regarding evaluation resources in order to streamline the referral process and minimize delays and stress for children, families and providers alike.
6+	The interdisciplinary team is preferred for diagnostic evaluation and intervention planning for older children and adolescents, as they may require a broad range of assessment procedures.
6+	Differential diagnosis necessitates careful attention to clinical features consistent with both ASD as well as other disorders of childhood that have overlapping and coexisting symptoms.
6+	Accurate identification and description of coexisting psychiatric conditions and consequent symptoms establishes the basis for quality intervention planning.
6+	An accurate and detailed family medical/psychiatric history and review of psychosocial factors, which may play a role in clinical symptom expression, is essential in the diagnostic process for the older child and adolescent.
6+	The collation and integration of multiple sources of information strengthens the reliability of the diagnosis; conclusions are weighted with respect to all evidence.
6+	The developmental disability and mental health service systems collaborate and cooperate to be effective in addressing the unique service needs of children with ASD.

6+	An assessment for intervention planning in older children includes an evaluation of skills and competencies required for transitions, such as the transition from elementary to middle school or from home to residential living.
6+	Assessment protocols should be designed to assist in development of functional curricular goals and intervention strategies that take advantage of the child's demonstrated skills and learning style.
Age	<i>Referral Process</i>
6+	Referring parties clearly identify the reason for referral, select the most appropriate evaluation resource, and share relevant information in a timely manner.
Age	<i>Components of a Diagnostic Evaluation/Assessment Process</i>
6+	Accuracy of assessment of older children and adolescents with adequate language skills requires a face-to-face interview.
6+	When the evaluation and assessment requires differential diagnosis of psychiatric disorders, the clinician seeks further referral and/or consultation when indicated.
6+	Because of wide variability in the expression of language ability among children and adolescents, a thorough communication assessment is a necessary component of the diagnostic evaluation.
6+	Evaluation of academic achievement is included in intervention planning when learning, behavioral or psychiatric disorders are suspected of playing a role in the older child's or adolescent's symptom presentation.

APPENDIX H: GUIDELINES FOR DIFFERENTIAL DIAGNOSIS OF DUALY DIAGNOSED CHILDREN⁵

General Diagnostic Guidelines

- The **diagnostic evaluation** should include a record review; a medical evaluation; a parent/caregiver interview; an interview and direct observation of the child/adolescent; a psychological evaluation; a communication assessment; an evaluation of social competence and functioning; a profile on restrictive behaviors, interests, and activities; and family functioning.
- It is important to find out **what prompted the screening** of the individual and why the individual was not screened earlier or has not presented with such features before. At times children are previously given the diagnosis of a significant cognitive impairment, particularly if they demonstrate “autistic tendencies” or “autistic traits” (p. 76). Other children are given a psychiatric diagnosis, such as a conduct disorder or ADHD, or a learning disorder.
- When psychiatric disorders may be present, a diagnostician can utilize, in addition to a mental status exam, **the following instruments**:
 - Diagnostic Interview Schedule for Children and Adolescents (DICA-R)
 - Schedule for Affective Disorders and Schizophrenia for School Age Children (K-SADS)
 - Minnesota Multiphasic Personality Inventory—Adolescence (MMPI-A).
 - Millon Clinical Multiaxial Inventory—Adolescence (MCMII-A)
 - Piers Harris Self-Esteem Scale
 - Achenbach Child Behavior Checklist—Youth Self Report
- Individuals with an ASD can exhibit **behavioral issues**, which at times occur as a secondary disorder, particularly with higher functioning individuals who are aware of their inability to succeed and function as their peers do. In addition, depression is common with these children and adolescents as well. In other individuals, the disorder may be interacting at a primary level along with the ASD, such as mental retardation, anxiety, and obsessive-compulsive disorder.
- Diagnosticians should consider that **some children may be misdiagnosed as having Asperger’s disorder or a PDD NOS**, when they display atypical behaviors that are actually a function of another psychiatric disorder, such as schizophrenia. There is still little research on this population of children, however it has been suggested that the manifestation of schizophrenia is extremely rare in children under the age of seven. When there is question of schizophrenia, or any

⁵ Summarized from California Department of Developmental Services (2002). *Autistic spectrum disorders: Best practice guidelines for screening, diagnosis, and assessment*. California. Retrieved 8/11/05 from <http://www.ddhealthinfo.org>.

other psychiatric disorder, an extensive psychiatric evaluation and gathering of family mental health history should take place.

Schizophrenia

- **Differential diagnosis in schizophrenia** should include a careful family history. A high familial loading of psychiatric illness (schizophrenia, bipolar disorder, etc.) indicates a strong possibility of schizophrenia rather than autism.
- **Cognitive function in children with schizophrenia** is typically within the borderline to low normal ranges of cognitive function on standard intelligence tests with nonverbal strengths relative to their language skills.
- **Social impairment in schizophrenia** is more aptly described as withdrawal. Children with schizophrenia are able to understand nonverbal social cues and the conventions of communication (turn-taking, eye gaze, etc.). While these skills may be less developed than in typically developing children, they usually surpass the skill set of children with ASDs.

Depression

- **Depression** is perhaps the most common coexisting syndrome found in children with ASDs. Higher functioning children with an awareness of their social limitations are particularly at risk of depression. Differential diagnosis of children with primary mood disorders vs. ASDs and comorbid depression can be made by gathering a careful history of the onset of symptoms. Children with primary mood disorders generally do not have a history of developmental delays; rather, they generally had a period of symptom-free functioning prior to onset of symptoms.

Anxiety

- **If anxiety is present** to the point of possible diagnosis, it is important to distinguish between the social shyness and avoidance that is displayed with individuals with an anxiety disorder versus the deficiencies in social impairment shown in individuals with an ASD.

Obsessive Compulsive Disorder

- When questions arise about **obsessive-compulsive disorder**, a diagnostician should determine whether the child or adolescent is showing signs of emotional distress over the obsessions or compulsions to engage in stereotypic or rigid behavior patterns. In individuals with an ASD, this ego-dystonic feature will often be absent from their repetitive interests and restrictive activities.

Attention Deficit Hyperactivity Disorder

- Children and adolescents are often **misdiagnosed with ADHD rather than an ASD** because of their impulsivity, limited empathy, excessive verbalization, and little awareness of personal space. However, it is important to look carefully at the level of attention in new and familiar situations. Children with ASD continue to display impairments in communication in familiar, structured settings. By

contrast, children with ADHD can sometimes display typical communication and behavior in structured or novel situations (such as a professional's office).

- Ability to focus on an activity may help clinicians **differentiate ASDs from ADHD**. Children with ASDs may focus on one activity that interests them for very long periods of time. Generally, children with ADHD cannot sustain attention to an activity for a extremely long period.
- **Children with ASD may display excessive motor activity**, such as hand flapping, spinning, or jumping. This is likely to occur when their time is unstructured or when expectations of them are not clear. They may appear most inattentive when the demands of a given task are beyond their capacity, when there are not strong motivating factors, or when relevance of the task is in question.

Oppositional Defiant and Conduct Disorder

- The diagnosis of **oppositional defiant disorder or conduct disorder** have been erroneously applied to adolescents with an ASD, particularly those with Asperger's disorder. It is important to point out that individuals with an ASD, even when aggressive rarely exhibit malicious intent when acting out behaviorally. Because of unawareness of social cues and norms, such children and adolescents are prone to act inappropriately in social situations (mostly through inappropriate verbalizations).

Tourette's Disorder

- Although Tourette's disorder may co-occur with an ADD, data claiming a higher prevalence in the ASD population is inconclusive. Clinicians must **distinguish between the vocal and motor tics of Tourette's from the stereotyped and repetitive behaviors and language anomalies found in ASDs**.

Schizoid Personality Disorder

- Researchers have identified several features which distinguish schizoid personality disorder from an ASD. Children with schizoid personality disorder appear less socially impaired but display marked disinterest in social contact; display lack of empathy with emotional detachment; evidence paranoid ideas; have a high rate of conduct disorders with malicious intent; have a higher familial loading of schizophrenia spectrum disorders.