Maine Developmental
Disabilities Council

Maine ASD Systems Development Project

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Final Report

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Goal 1: Improve public Health and Social Service Capacity for Screening and Referral of Children with ASD.

☑ ***Objective 1.1 and 1.2 Maine will have developed and adopted standardized screening and referral protocols for the initial identification of possible ASDs in young children which will have been tested and implemented in all HeadStart, WIC, Public Health Nurses and Home Visitors.***

WIC *(Italic print is a Direct Excerpt from pages 1-5 of Altarum's Final Evaluation Report)*

The role of WIC clinics in identifying and referring children with autism spectrum disorders is less straightforward, as the staff are generally trained in nutrition and not in child development. However, since a wide range of children are seen in WIC clinics, it is useful for their staff to have some knowledge of the signs of ASDs and how to refer and support their families.

During the first year of the grant State Autism Implementation Grant Manager (AIG Manager) met with a team from the Special Supplemental Nutrition Program for Women, Infants and Children (known as WIC). They reported that they didn't have the ability to screen for autism at that time. In fact, they were struggling to find funds to screen for lead because the USDA would not provide reimbursement. However, WIC did want their staff to have a basic training about recognizing the first signs of autism and what to do if they suspect a child may have an ASD. The Maine Developmental Disabilities Council (MDDC) increased the Autism Society of Maine's (ASM) contract to provide trainings to WIC staff.

Early in the second year of the contract ASM reported that they had significant difficulty scheduling the trainings as the WIC offices appeared to not find the information relevant. After a great deal of effort, which included a phone call stressing the importance of the training from the AIG manager, 42 WIC agency staff was trained. Below is Altarum's results of the evaluation.

The baseline survey of 37 WIC agency staff found that the majority were not familiar with the signs of autism. Only 35.1 percent knew the earliest "red flag" for autism, and 40.5 percent responded correctly to the question about early communication impairments. Between 78 and 83 percent had not heard of each of the relevant screening tools, and 73.0 percent reported that they never screened for autism in their agencies (which is not surprising). Similarly, WIC agency staff have generally received no training in talking to families about autism (75.7 percent), and 45.9 percent report that they would feel "not at all comfortable" in this situation. About one-third would feel somewhat comfortable, and 13.5 percent would feel moderately comfortable.

Nonetheless, 43.2 percent reported that their agencies had a system in place for referring children who are exhibiting signs of autism: 13.5 percent reported having a well-established system and 29.7 had a system that could use improvement. Only 27.0 percent reported having no such system, and 24.3 percent were not sure. Overall, 70.2 percent reported that they would refer such a child to CDS, and 35.1 percent would refer to the child's primary medical provider.

The baseline survey revealed a clear need for training among staff of WIC agencies if these offices are to be relied on as sources of identification and referral of children who might have ASDs or other developmental disabilities. Although a follow-up was not conducted for this group, it appears from the baseline survey that annual training and follow-up resources would be very helpful for this constituency.

Head Start/CDS *(Italic print is a Direct Excerpt from pages 1-5 of Altarum's Final Evaluation Report)*

In hopes that this work would be sustainable in an ever-changing staffing environment Maine created a DVD with accompanying curriculum. The M-CHAT movie was separated into six primary chapters so that individuals can customize the training to include the information that is most relevant for their audience. The chapters are as follows:

Chapter #	Description	Duration
	Introduction	4 minutes
1	Why is universal screening for autism important?	2 minutes
2	First Signs of ASD	6 minutes
3	M-CHAT Part 1, Administration and Scoring	7 minutes
4	M-CHAT Part 2, Follow-up Interview	8 minutes
5	How to Talk to Families About Screening	4 minutes
6	Introduction to ASQ	5 minutes
	Conclusion	1 minute

In addition to the video, trainers receive the following curriculum:

- Screening answer scenarios that can be used within a training session to practice administering the M-CHAT. Pair up your participant and have one person administer the test while the other person answers from the example sheets. The two participants can then score the screen together.
- Print out of the PowerPoint presented at the train-the-trainer training.
- A sample addressed to physicians to accompany an M-CHAT that needs referral.
- A copy of the M-CHAT part 1 with scoring instructions.
- A copy of the M-CHAT part 2.

In total, 170 individuals received the train-the-trainer seminar as described above and an additional 130 DVD's were mailed to individuals on request. Below includes Altarum's evaluation of the training.

Over the first two years of the project, the Maine DD Council conducted trainings for staff of Head Start and CDS agencies in screening children for ASDs. These trainings were provided via a DVD that covered six topics, including the importance of universal screening, the first signs of ASDs, the administration and scoring of the M-CHAT, the use of the M-CHAT follow-up interview tool, how to talk to families about screening, and an introduction to the Ages and Stages Questionnaire (ASQ). During the project's second year, 42 WIC staff and 170 early childhood professionals (staff of Head Start and CDS) were trained. Because of cuts to the state budget, it was not possible to train home visitors or public health nursing staff.

There were 77 responses to the baseline survey from Head Start, local health department, and CDS employees.
The first knowledge question asked about one of the earliest "red flags" for autism. The correct answer, lack of response to one's name, was chosen by 36.3 percent of respondents. On the second question, regarding which early communication impairment is especially suggestive of autism, 64.9 percent chose the correct answer (lack of pointing to indicate wants and needs). These results show a need for additional training on basic aspects of autism spectrum disorders for this group of professionals.

Table 1 below shows the respondents' level of familiarity with three major screening tools used to identify children with ASDs. The M-CHAT and the Ages and Stages Questionnaire were familiar to most respondents, but no tool had been used by a majority of respondents.

Table 1
Head Start/CDS Respondents' Level of Familiarity with Screening Tools

	Have not heard of this tool		*Have heard of it, but have not used it*		*Have used this tool*		*No response*	
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*
M-CHAT	*15*	*19.5*	*51*	*66.2*	*9*	*11.7*	*2*	*2.6*
ASQ	*9*	*11.7*	*30*	*39.0*	*38*	*49.4*	*0*	*0*
PEDS	*42*	*54.5*	*30*	*39.0*	*2*	*2.6*	*3*	*3.9*

Just over half of respondents (57.1 percent) report that they were very comfortable or moderately comfortable speaking to families about a child displaying signs of autism or the need to refer the child for further assessment. One-third reported that they were somewhat comfortable in this situation, and 7.8 percent said that they were not at all comfortable. This level of comfort may be related to the amount of training respondents reported receiving from their agencies on how to talk to parents about autism: only 3.9 percent reported receiving comprehensive training, but 41.6 percent received some training. About half (51.9 percent) reported that they had received no training.

Screening practices within public health agencies were similarly varied. When asked whether their agencies routinely screened for autism, over one-third of respondents (36.4 percent) said "no, never." Only 10.4 percent said that they routinely screened using the M-CHAT, 23.4 percent screened with informal questions, and 11.7 percent routinely screened with another instrument, generally the Ages and Stages Questionnaire. Another 16.9 percent reported that they screened only if parents raised concerns.

Not surprisingly, respondents reported a number of barriers to screening for autism in their agencies. Lack of familiarity with screening instruments was checked by 50.6 percent, lack of time during visits by 6.5 percent, lack of funding for screening by 7.8 percent, and 11.3 percent write in another barrier. These included parents' consent, lack of knowledge or training, or a general statement that "we don't screen." Nearly one-quarter of respondents (22.0 percent) listed no obstacles to screening.

After the workshop, participants based in Head Start, CDS, and other community providers' offices were sent a link to a brief online survey that asked similar questions to the baseline survey, without the knowledge questions and with the addition of questions about how screening and referral practices had changed since the training. Twenty-six people responded to the survey, and 23 of them completed it.

Of the 26 respondents, 14 work for CDS offices, 8 for Head Start or Early Head Start programs, two for medical or public health offices, and two for other agencies. The occupations of the respondents were more varied: 5 listed their occupation as home visitor, 6 as case manager, 2 as teacher or educator, 3 as Speech and Language Pathologist, 4 as program manager, 1 as a consultant, 2 as medical providers, and 2 left the question blank.

Screening and referral systems appear to have changed somewhat since the training. Of the 26 respondents, half reported that they are screening children for ASDs using the M-CHAT. Four (15.4 percent) are screening with informal questions, two are using the ASQ, and three are screening only if parents raise concerns. Three reported that they do not screen and one left the question blank. When asked about how the training affected their knowledge about how to administer and score standard screening tools, 16 (61.5 percent) reported that their knowledge had increased greatly, and an additional 8 (30.8 percent) said that it had increased somewhat. One said that this question did not apply because she was already knowledgeable, and one left the question blank.

Despite the inconsistency in screening, 17 respondents (65.4 percent) reported that they have a system in place for referring children for additional evaluation or follow-up, and an additional 6 (23.0 percent) said they had such a system but it needed improvement. Only one said they had no such system and two left the question blank. There was considerable diversity in where respondents refer: CDS and specialty medical providers were selected by 7 respondents each (26.9 percent), while 3 reported that they refer to primary medical providers, 2 to primary care providers and CDS, 1 to special education, 2 to other resources, and 3 left the question blank. Half of the respondents had referred at least one child since the training: 10 reported that they had referred between 1 and 5 children, and 3 had referred 6 to 10 children. (Five had referred no children, 4 marked this question as not applicable because they did not refer, and four left the question blank.) Seven reported that they had seen a small increase in the number of children they referred since the training, while 14 reported no increase. The remaining 5 marked the question as not applicable or left it blank.

When asked about the impact of the training on their agencies' referral systems, the majority (16 respondents, or 61.5 percent) said that it had improved somewhat, and an additional two reported that it had improved greatly. Three said that it had improved very little or not at all, and the remaining five marked the question as not applicable or left it blank.

Respondents also had positive reports about the impact of the training on their level of comfort speaking to families whose children showed signs of autism or needed to be referred for further evaluation or treatment. Ten (38.5 percent) reported that their comfort level had improved greatly, and another 10 said it had improved somewhat. Of the remaining 6, 3left the question blank, 1 marked it as not applicable, and 2 said it had improved very little or not at all.

Goal 2: Expand the role of private medical providers in screening, diagnosis and treatment of ASDs

☑ *Objective 2.1 Expand the number of family physicians, pediatricians, nurse practitioners, and other medical professionals using universal screening and referral tools and protocols to identify children with possible ASDs.*

Grand Round Trainings

Originally the AIG had planned to conduct 14 discrete grand round presentations aimed at increasing screening all children for autism. By the end of the third year of the grant 208 physicians were trained under this method at 7 locations. Mid grant term the State of Maine received a CHIPRA grant and conducted a Quality Improvement Process with supported Plan-Do-Study-Act cycles. Twelve pediatric and family practices engaged in this process from around the State. In hopes of reducing duplication of effort the AIG chose to partner with the Improving Developmental, Autism, and Lead Screening for Children effort conducted by Improving Health Outcomes for Children (IHOC) The AIG were considered the content experts and took worked with IHOC on the selection topics of agenda items and presentations. Information was delivered via two day-long learning sessions and supportive conference calls and webinars.

According to the evaluation report of this initiative, the developmental and autism screening rates of children receiving MaineCare more than doubled in all age groups. Practices included 45 physicians and an estimated 20,000 MaineCare children were impacted by this effort. Autism screening using the M-CHAT increase from 56% to 82%. Perhaps even more crucial to systemic change for autisms screening is physicians expressed that they had learned from the learning initiative that many of their patience were being screened by community-based service agencies. This recognition, we hope, will assist in an increased effort to coordinate screening and care for children.

Another benefit that occurred while working with IHOC was the discovery that any developmental screening could be billed under the CPT code 96110. Over the past number of years the ASD Systems Change Initiative and the Autism Implementation Grant had been recommending to physicians that they use that code for autism screenings. This created challenges, however, in measuring the success rates of our efforts because 96110 could be used for multiple screenings. Upon this discovery MaineCare developed a modifier just for autism screening. Even more encouraging is that MaineCare adopted a rate for the follow up interview necessary to a complete, comprehensive screen. We hope that this will create an incentive for physicians to follow-up with the complete autism screen as opposed to just the first part.

CPT Codes for Billing of Global Developmental and Autism-Specific Screening Tools				
CPT	**Modifier**	**Description of Service**	**Applicable Screening Tool**	**Rate**
96110	None	developmental screening w/interpretation & report, standard form	Global developmental screening tool (i.e., ASQ, PEDS)	$8.99
96110	HI	developmental screening w/interpretation & report, standard form	Autism-specific screening tool (MCHAT-1)	$8.99
96111	HK	developmental testing w/interpretation & report	Autism-specific screening tool (MCHAT-2 *only*)	$86.59

☑ *Objective 2.2 Improve and expand the availability of diagnostic and treatment services for children and youth with ASDs by qualified medical practitioners*

Build Capacity for PDD Physician Training Project *(Italic print is a Direct Excerpt from pages 14-20 of Altarum's Final Evaluation Report)*

In January 2013, as part of the Maine Autism Spectrum Disorders Systems Development Initiative, several developmental/behavioral physicians in the state were trained by Carol Hubbard, MD to conduct workshops for primary care providers (pediatricians and family physicians) on identifying and following children with autism spectrum disorders. Overall, ***94 providers*** *participated in the training workshops presented by three providers: 35 attended the training presented by Dr. Gellerstedt at EMMC 17 attended the training conducted by Dr. Silverstein, and 42 attended Dr. Meister's trainings. While the workshops were based on a consistent curriculum, each session was tailored to the specific needs and interests of the participants, who varied in their specialty, level of experience, and background.*

To evaluate these workshops, participants were given survey questionnaires assessing their knowledge about ASDs, their opinions about the developmental prospects of children with ASDs, and their processes and practices for providing care to these children. The baseline, pre-workshop survey was administered before the workshop, and the post-workshop survey was sent several weeks afterward. We received 41 pre-workshop surveys and 25 post-workshop surveys across all three sets of training sessions. The findings of these surveys are summarized below.

A. Demographics

The respondents to this survey were predominantly family physicians, with 13 pediatricians (one of whom did not provide information about his or her age or sex) and 4 other providers, one a therapist and one a nurse practitioner, and two who did not list their specialty. Although they were relatively recently trained, the majority of pre-workshop respondents did not feel that they had had adequate training in either screening and recognizing ASDs or caring for and following children with ASDs. This *was true of both pediatricians and family physicians. Of course, this is not a random sample and those who chose to attend these workshops may be more likely to feel relatively uninformed on these topics.*

Table 7. **Pre-Workshop Survey Responses about Adequacy of their Training about ASDs***				
	Strongly agree	Agree	Disagree	Strongly disagree
Screening/recognizing ASDs	1	9	19	8
Caring for and following children with ASDs	1	5	23	8
*4 records missing responses to these questions				

B. Knowledge

Participants were asked a series of factual questions on ASDs, based on the definition in the DSM-V. Table 3a shows the responses to these questions by specialty (excluding the one therapist and the three respondents who did not name their specialty). One of the pediatricians and one of the family physicians did not respond to these questions, so this analysis represents the responses of 14 pediatricians and 22 family practitioners, including nurse practitioners.
As Table 8a shows, the majority of pediatricians answered the first three questions correctly. On the fourth question, the characteristics of ASDs as described in the DSM-V, each of the pediatricians who answered the question only checked off one answer, when all were applicable.

Few of the family physicians (6 of 23) were able to identify the earliest red flag for autism, lack of response to one's name; the majority thought it was hypersensitivity to touch or loud noises. A majority did know the early communication impairment and the area of impairment most central to an autism diagnosis. On the DSM-V criteria, six checked off all three options.

Table 8a. **Pre-Workshop Survey Responses to Knowledge Questions, by Specialty: Number and Percent who Correctly Answered Each Question**						
Question	Pediatrics		Family Practice		Total	
	N	%	N	%	N	%
Specific early sign (lack of response to name)	12	80	6	27	18	49
Early communication impairment (pointing)	14	100	16	72	30	83
Impairment central to autism diagnosis (reciprocal social delays)	11	79	13	59	24	67
Found in ASDs according to DSM-V	0	0	6	27	6	17

After the workshop, the pediatricians continued to answer the first three questions correctly, but none checked all three options for the fourth question. The responses among the family physicians improved considerably, with at least half answering each question correctly.

Table 8b.
Post-Workshop Survey Responses to Knowledge Questions, by Specialty:
Number and Percent who Correctly Answered Each Question

Question	Pediatrics		Family Practice		Total	
	N	%	n	%	N	%
Specific early sign (lack of response to name)	7	100	14	78	21	81
Early communication impairment (pointing)	7	100	17	94	24	92
Impairment central to autism diagnosis	6	85	11	61	17	65
Found in ASDs according to DSM-V	0	0	9	50	9	35

Participants were also asked about the components of a standard examination for a nonverbal 3-year-old with autism, as well as the therapies that are most likely to improve the core features of autism. For the exam, the correct answers were an audiology examination and Fragile X and karyotype; comparative genomic hybridization is newer and its efficacy is being debated. EEG and cranial MRI are indicated only if specific neurological symptoms are present. Prior to the workshop, all of both the pediatricians the family physicians correctly identified an audiology evaluation as part of the workup, and four physicians in each specialty identified the Fragile X and karyotype. Two pediatricians and one family physician did not respond to this question.

Treatment modalities generally recommended for ASDs include speech and language therapy, social skills training, applied behavioral analysis (ABA), and often occupational therapy. Physical therapy and supportive psychotherapy are not generally indicated for these diagnoses. In the baseline survey, half of the pediatricians recommended occupational therapy and half recommended speech and language therapy; ABA and social skills training were recommended by one pediatrician each. Among the family physicians, a majority recommended social skills training (21), occupational therapy (18), speech therapy (18) and ABA (13). Pediatricians seemed less informed about effective treatments; although all 13 responding pediatricians recommended social skills training, fewer recommended speech therapy (7), occupational therapy (2), or ABA (1).

Table 9a.
Pre-Workshop Responses to Knowledge Questions by Specialty: Number and Percent Recommending Each Evaluation Method or Therapy

Question	Pediatrics		Family Practice		Total	
	N	%	N	%	N	%
Components of standard medical exam for a nonverbal 3-year-old child with autism						
EEG	2	15	0	0	2	6
Cranial MRI	3	23	1	5	4	12
Fragile X and Karyotype	6	46	8	38	14	41
Audiology evaluation	13	100	21	100	34	100
Comparative genomic hybridization	4	31	4	19	8	24
Therapies likely to improve core features of autism in a child with an ASD						
Occupational therapy	2	15	18	82	20	57
Physical therapy	3	23	10	45	13	37
Speech and language therapy	7	54	18	82	25	71
Individual or group social skills training	13	100	21	95	34	97
Supportive psychotherapy	4	31	10	45	14	40
Applied Behavioral Analysis (ABA)	1	8	13	59	14	40

After the workshops, a larger proportion of respondents recognized the value of Fragile X and karyotype for evaluation, although several family physicians recommended EEGs, cranial MRIs, and comparative genomic hybridization. In the area of therapy, the family physicians were unanimous in their recommendation of speech and language therapy, occupational therapy, social skills training, and ABA. A large majority of family physicians recommended occupational therapy (89 percent) and speech and language therapy (83 percent), and most recommended ABA (55 percent). Among pediatricians, all recommended speech and language therapy, and most supported occupational therapy (86 percent) and social skills training (71 percent). Most pediatricians also recommended physical therapy (71 percent).

Table 9b.
Post-Workshop Responses to Knowledge Questions by Specialty:
Number and Percent Recommending Each Evaluation Method or Therapy

Question	Pediatrics		Family Practice		Total	
	N	%	N	%	N	%
Components of standard medical exam for a nonverbal 3-year-old child with autism						
EEG	0	0	6	33	6	24
Cranial MRI	0	0	6	33	6	24
Fragile X and Karyotype	2	29	14	78	16	64
Audiology evaluation	6	86	16	89	22	88
Comparative genomic hybridization	1	14	5	26	6	24
Therapies likely to improve core features of autism in a child with an ASD						
Occupational therapy	6	86	16	89	22	88
Physical therapy	5	71	4	22	9	36
Speech and language therapy	7	100	15	83	22	88
Individual or group social skills training	5	71	8	44	22	88
Supportive psychotherapy	2	29	2	11	4	16
Applied Behavioral Analysis (ABA)	7	100	10	55	20	80

On both surveys, respondents were asked to rate their level of agreement with a series of statements about the diagnosis and prognosis of children with ASDs. A response of "strongly agree" was scored as 1 and "strongly disagree" as 4. Table 10 below shows the mean scores on these questions from respondents before and after the workshops. In general, the level of agreement with most statements went up after the workshop (that is, the scores were lower), with the greatest change seen in the level of agreement with the statement that most children with ASDs also have intellectual disabilities and that most children with ASDs also have gastrointestinal issues, such as diarrhea, constipation, and food allergies. The only statement for which respondents were more likely to disagree after the workshop was that individuals with ASDs are likely to live independently as adults.

Table 10.
Mean Pre- and Post-Workshop Responses to Opinion Questions

	Pre	Post
Most children with ASDs also have intellectual disabilities	2.6	2.3
ASDs are often associated with behavior issues	2.0	1.8
Most autistic children do not talk	3.1	3.0
Autistic children often have GI issues	2.4	1.9
Autistic children rarely form social attachments, even to family members	2.9	2.7
With proper treatment, most autistic children eventually outgrow their autism	3.2	3.0
Specialized diets and supplements may improve symptoms of children with ASDs	2.7	2.5
Individuals with ASDs are likely to live independently as adults	2.3	2.5

Respondents were also asked to rate their own level of knowledge of several aspects of autism treatment. As shown in Table 11a, most respondents stated that they had little knowledge in nearly every area. Following the workshops, a greater number of respondents ranked themselves as "familiar" or "knowledgeable" in more areas, particularly medical treatment and educational services and advocacy.

Table 11a.
Pre-Workshop Respondents' Ratings of their knowledge of Autism

	Very knowledgeable	Knowledgeable	Familiar	Have little knowledge
Medical treatment	0	7	15	17
Complementary and alternative therapies	0	1	14	23
Behavioral guidance	1	3	21	14
Educational services and advocacy	0	8	19	12
Transition to adulthood	2	0	13	24

Table 11a.
Pre-Workshop Respondents' Ratings of their knowledge of Autism

	Very knowledgeable	Knowledgeable	Familiar	Have little knowledge
Medical treatment	0	11	10	3
Complementary and alternative therapies	0	3	18	3
Behavioral guidance	0	5	16	3
Educational services and advocacy	0	11	11	2
Transition to adulthood	0	2	12	10

Process

Prior to the workshop, respondents were asked about their level of comfort caring for children with specific chronic conditions. More than half of respondents noted that they were uncomfortable providing ongoing care to children with ASDs, while most were at least somewhat comfortable caring for children with ADHD, and a large majority were comfortable caring for children with chronic physical conditions such as asthma. Following the workshop, a greater number of respondents reported themselves to be "somewhat comfortable" following children with ASDs, while their comfort level with the other conditions did not change.

Table 12.
Pre-Workshop Respondents' Comfort with Specific Conditions

	Very comfortable		Comfortable		Somewhat comfortable		Uncomfortable	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
ASDs	1	1	10	4	14	11	14	5
ADHD	10	7	13	5	13	6	3	3
Chronic illness	13	5	17	11	7	4	2	1

Providers were asked how they routinely screen the development of their pediatric patients. Prior to the workshop, 8 respondents reported that they used the EMR or other checklist; 3 each reported using the PEDS, 5 used the ASQ, and 2 used the Denver screen. Five more used another unspecified screen, or informal questions; and 14 reported using a combination of approaches. Regarding screening for autism, 28 reported that they used the MCHAT, primarily at 18 and 24 months. Following the workshop, 15 reported screening with the EMR, 10 with the ASQ, 6 with the PEDS, and 4 with the Denver II. In addition, to screen for autism, 23 reported using the MCHAT, generally at 18 (or 18 and 24) months.

Respondents were then asked what their next step was if they are concerned that a patient may have autism. Prior to the workshop, none reported that they would do further assessments themselves. Rather, two said they would refer to CDS if a child was 5 or younger, and 13 said they would refer a specialist for further evaluation, and the remaining 25 said they would refer simultaneously to a specialist and to CDS (for a child aged 5 or younger). After the workshop, 2 said they would conduct further assessments themselves, two would refer to a specialist, one would refer to CDS, and the remaining 19 would refer to both CDS and a specialist simultaneously.

Prior to the workshop, respondents were asked what obstacles prevented them from screening for autism. The one most commonly checked was lack of familiarity with screening instruments (23), followed by lack of time during office visits (19); 17 of these respondents checked both of these responses. Pre-workshop respondents were also asked what obstacles prevented them from providing follow-up care to children with autism. Twenty-three mentioned lack of time during office visits; 22 a lack of knowledge or training; 9 a lack of a non-physician staff member to help coordinate care; 7 that families prefer to see a specialist; and 2 a lack of communication from specialists.

Finally, respondents were asked about their coordination with the educational system and other providers for children with ASDs in their practices. Prior to the workshop, 18 respondents reported that they rarely spoke with either teachers or other education staff and 16 rarely spoke with community case managers; 12 reported that they occasionally spoke with teachers (about once a year), and 14 occasionally spoke with case managers. Likewise, nearly all (34) said that they generally did not attend IEP/IFSP meetings for their patients with ASDs, and 15 reported that even if they had adequate knowledge and training in providing follow-up care for children with ASDs, they would prefer to have a specialist involved. These numbers did not change after the workshop; 11 still reported that they rarely spoke with educational staff or care coordinators, and 6 occasionally did so, and 23 reported that they generally did not attend IEP/IFSP meetings.

D. Discussion

Overall, the workshops succeeded in providing basic information about autism spectrum disorders to a group of primary care providers who considered themselves uninformed on the topic and lacked confidence in following children with this diagnosis. Most reported that they did not see many children with ASDs in their practices, however, so it is unclear whether they will be able to put their knowledge into practice. As was suggested by one of the training coordinators, analysis of MaineCare claims data might provide information about whether the MCHAT for screening was actually being used at a greater rate for autism screening.

Web Based Curriculum for Physician Office Staff.

Carol Hubbard MD completed the taping of the webinar using Adobe Connect. The AIG subcontracted with MaineCite to produce and work on the evaluation of the webinar. Unfortunately, there were difficulties with Adobe Connect and the first copy was corrupted. MaineCite contacted the AIG Coordinator with the news that the issue has been resolved and the webinar is now ready. The MDDC will be posting the webinar on its website shortly and the plan to publicize the presentation will occur.

☑ ***Objective 2.3 Improve and expand the capacity of primary and specialty care providers to address the ongoing treatment needs of children and youth with ASDs, including underlying medical conditions and ongoing preventative care.*** *(Below, in italic, are the results of the surveys and focus groups conducted by Altarum Institute to identify medical professionals gaps in knowledge regarding medical care, treatment and transitioning)*

> *"To survive as a parent of a child with autism, you have to be an expert and fight for your services and your child."*
>
> —physician (focus group)
>
> *"Autistic patients come with very fractionated care. For example, some may have a group home, a day program, a primary care [physician], neurologist—and yet there is no real communication between them. I [the mental health professional] am left out and don't find out about the coordination of care]meeting until 6 months later! And I am the mental health provider on record."*
>
> —physician (focus group)
>
> *"I have to do all the coordination of care myself…. There is zero communication between school-based services, OT, PT, and the doctor. A team approach is needed!"*
>
> —parent (survey)
>
> *"[If I had a magic wand and could change anything about accessing health care for my ASD child], I would have more doctors trained to, at the very least, recognize autism when it is right in front of them."*
>
> —parent (survey)
>
> *"It is a very piecemeal system with no one having a solid knowledge of all the programs, needs, and best practices. If I have cancer, I can go to the cancer wing and get solid treatment…. Why doesn't every major hospital have an autism wing where behavior, diet, ABA, therapy, OT, speech, meds…are established?"*
>
> —parent (survey)

Introduction

Altarum Institute was contracted by the Maine Developmental Disabilities Council (MDDC) to appraise medical professionals', parents', and self-advocates' knowledge regarding health needs and services for adults with autism spectrum disorder (ASD). This project is a component of the Maine Autism Spectrum Disorders Systems Development Initiative.

This report specifically addresses the issue of expanding the role of private medical providers in transitioning minors with ASD to adult services, as well as collecting and synthesizing transition and health care data from parents of persons with ASD and from self-advocates with ASD.

Methods

Altarum implemented a mixed-methods approach using both quantitative and qualitative data to assess physicians', parents' and self-advocates' opinions regarding service delivery to persons with ASD. Quantitative methods include data collected through two unique surveys: one for parents of persons with ASD and one for ASD self-advocates. Appendixes B and C contains the surveys.

Qualitative methods included a physician focus group and a physician group interview. Appendix A contains the focus group protocol. The focus group protocol was also used for the group interview. Focus groups are designed to elicit the full range of ideas, attitudes, experiences, and opinions held by a selected sample of respondents on a defined topic. In this case, the respondents are physicians in Southern Maine, and the topic is physicians' current state of knowledge regarding ASD, transition issues, and training and resource needs for ASD. Through focused interaction on these questions, participants provided a wealth of qualitative data not available from written surveys alone. Participants were targeted due to background characteristics of special interest. The focus group facilitator elicited discussion on motivations, feelings, and beliefs. To elicit opinions from participants the facilitator used tactical probing and restated questions. Through this focus group, we learned what factors are most salient to participants regarding improvement of care for persons with ASD, the level and nature of emotional value associated with those factors, and ways in which participants differ on key issues.

Because of the small numbers involved, however, the participants cannot be expected to be representative in a statistical sense of all specialist physicians, and findings cannot reliably be generalized beyond their number.

Focus Group Recruitment and Facilitation

The recruiting process was completed three times with one focus group and one group interview fulfilled in the end. Recruitment was conducted by Gloria Aponte Clarke for the first two focus group attempts. A physician list utilized by the Morrison Center[i] *as well as physician contacts at Maine Medical Center Family Practice*[ii] *and InterMed*[iii] *received letters of invitation by postal mail and e-mail. The February 28 focus group could not be conducted, as an insufficient number was recruited (only three persons). The March 27 focus group was recast as a group discussion, with two physicians attending. The third focus group, conducted on June 6, was primarily recruited by Dr. Carol Hubbard of Maine Medical Partners using her professional contacts and proceeded with a sufficient number of focus group attendees (seven persons).*

Table 1: Focus Group Detail

Date	Number Registered	Number Attended	Location	Outcome
February 28, 2012	3	n/a	Pepper Club	Did not occur
March 27, 2012	2	2	MMC Family Practice	Group interview
June 6, 2012	7	7	Pepper Club	Focus group

The focus group facilitator was Gloria Aponte Clarke of Altarum. During the focus group, the facilitator read the questions from the discussion guide and probed when necessary to foster discussion. Probing was minimal, as discussion was plentiful and animated. A digital Sony audio recorder with speed control was used with participants' consent.

Locations

The group meeting scheduled for February 28, which did not occur, was to be at the Pepper Club Restaurant on Middle Street in Portland, Maine. Dinner would have been provided for this evening focus group.

The group meeting scheduled for March 27 was to be held at MMC Family Practice on Congress Street in Portland. The group discussion was conducted at this location in a conference room and lunch was provided. The group meeting on June 6 was conducted at the Pepper Club Restaurant on Middle Street in Portland. Dinner was provided for this evening focus group.

Survey Methods

An online survey was developed to best reach parents of persons with autism as well as self-advocates with autism. The survey covered topics related to access and barriers to primary and specialty care, and the quality of primary care for children with ASD. The survey link was sent by the Maine Developmental Disabilities Council in order to facilitate recognition, validity, and importance of the survey. The MDDC sent the parent survey via e-mail to 75 people and eight organizations for distribution. The self-advocate survey was sent to two contacts for further distribution. The survey was accessed by the respondent opening the invitation e-mail and clicking on the live survey link.

The survey link was distributed on June 8 and was live for a period of three weeks. Two reminder e-mails were sent by the MDDC to potential respondents. In order to increase response rates, respondents were entered in a raffle for an iPod Shuffle.

Data Analysis

A systematic approach to qualitative data analysis was employed, which ensured quality and consistency of analysis and facilitated the systematic identification of themes, deviations from themes, interesting stories, lessons learned, and recommendations.

Focus groups were analyzed using a tape-based analysis, which involves the systematic review of the recorded discussion, supplemented by the moderator notes taken during or shortly after the conclusion of the focus group. The audio file was reviewed for frequency and extensiveness of themes and patterns in participants' responses. Five concepts were maintained throughout this review: the frequency of statements, repetition of similar statements, the intensity of the comments, the internal consistency of the comments, and the specificity of responses.

The survey data was collected using a Web-based application. A Microsoft Excel spreadsheet was generated from the Web-based application allowing for an analysis of responses. Frequencies and percentages were calculated for each question.

Characteristics of Respondents

The participants of the focus group and the group discussion were all medical doctors (MD). The participants of the focus group were MDs with representation from the specialties of psychiatry (two), neurology (two), child neurology (one), developmental pediatrics (one), and internal medicine (one). The group discussion members were both practicing Family Physicians.

Below is a table illustrating the demographics of the parent survey respondents.

Parent Survey Respondent Characteristics N = 37

	Total
Age	
25–34	3
35–44	14
45–54	10
55–60	4
Relationship to Person with ASD	
Father	4
Mother	30
Number of Children	
1–2	24
3–4	11
5+	1
Highest Level of School	
College	22
High school	6
Less than 6th grade	1
Trade or technical school	6

Unfortunately, there were only three respondents to the self-advocate survey. Results of the self-advocate survey will not be discussed due to the low response rate.

Overarching Themes

The process of examining the data from the focus group, interview and parent survey resulted in the following overarching themes regarding ASD: knowledge, training, practice pressures, transition, barriers to care and suggestions.

Knowledge of ASD

The current state of awareness and understanding of ASD among physicians was largely unknown at the onset of this project. It became very clear through the process of recruiting for the focus groups as well as conducting the focus group that lack of knowledge was a central issue.

Nearly 50 physicians were contacted during focus group recruitment. Phone calls made to physicians' offices provided interesting anecdotal information. The nurses representing the physicians often stated something to the effect of "He doesn't have any autistic patients. He doesn't have time to go to any groups."

The conversations which occurred with family physicians were enlightening. One physician stated, "I really don't know much at all about ASD." What they know about ASD has been self-taught. Their perception is that they do not have autistic patients in their patient panel. They did contemplate after the discussion whether that was actually the case. The physicians also stated that they had heard about the increase in numbers in autistic children through the popular media and were curious to know the popular media was reporting was accurate. They requested data as to incidence and prevalence of ASD in Maine.

During the focus group with specialists, the tone regarding knowledge was different. They were aware of patients with ASD in their practices. In fact, they were aware and discouraged by the complexity of the cases and the uncoordinated care their patients with ASD received. Some of the specialists acknowledged ASD in their training, but in a manner addressing only their area of expertise. Thus, the individual specialist is addressing one small part of a person with ASD. The physicians reported that the disjointed approach that is inherent in our health care system is especially harmful to a person with ASD.

Training

The focus group and interviews assessed the level of training received by physicians in the past as well as desire for future training.

The family practitioners interviewed had not received formal training in medical school or during residency. When asked how physicians could learn about ASD, one physician stated, "The topic has to be clinically relevant…. Right now, people don't see [ASD] as an issue." The physicians stated that because most physicians do not think that they have patients with ASD in their practice, they are not prompted to learn about ASD.

The physicians stated that if they had a larger number of ASD patients then they would be motivated to learn more about ASD. If they had an "influx," then the format of a lunch-and-learn would be accepted, because it would be clinically relevant to them. They stated, "Right now, as far as I know, we don't have the volume [of ASD], so physicians wouldn't be interested." Both physicians were clear to state, "Just to go to a random lecture doesn't do anything for you." Webinars were not seen as a good method of educating physicians. One physician stated, "I have good intentions for webinars, but I just don't do it. I am just too busy." The physicians stated that a session about ASD and information at a conference would be well received by their colleagues.

The specialists agreed with the family physicians. As a group, the specialists had many questions regarding the recommended and evolving care of persons with ASD. They stated that grand rounds, a conference, and a listserv would be optimal ways for physicians to learn about ASD. The specialists were also concerned with the lack of knowledge among primary care physicians: "Training is very, very needed. Getting primary care practices more comfortable doing follow up care is very important. Having them comfortable with [gastrointestinal] issues, etc. is critical."

Practice Pressures

The specialist physicians reported that pressure from administrators to perform billable work was significant. Much of the conversation at the focus group centered on the type of work that is integral to a person with ASD but unbillable by insurance companies. The following quotation exemplifies the sentiment: "The pressure in my group is to generate RDUs and do procedures. I am not supposed to do any 'social-worky' things. What we need to be able to do is to bill for management of the ASD patient, which would then in turn save insurance companies money."

There was a fervent discussion regarding the care that persons with ASD need to thrive and the discrepancy with what services are billable. A physician summarizes the thought well in the following quotation: "We don't have a health care system that pays for this kind of coordinated care. Until we can change the payment structure it is hard for me to believe that we can provide the care needed."

Another challenge for physicians lay in the very nature of the medical model. Physicians noted that the medical model does not mesh with treating ASD: "This is going to make doctors sound really bad…but I do think that because there isn't a pill that we can prescribe to treat ASD, that makes doctors less interested in ASD."

Transitions

The issue of transitions for persons with ASD were reported as being severe and exacerbated by the health care system. A dynamic and passionate discussion ensued motivated by the belief that systems could be created and greatly improve outcomes for persons with ASD. Physicians reported that many transitions for persons with ASD were a trigger for behavior issues and that, with some planning and coordination, many of the triggers are possible to avoid.

The transition that was discussed most often as being most difficult for persons with ASD is leaving school and the ancillary services associated with school. A physician states the issue well in the following quotation: "It is a complete crisis when they leave school. It is like falling off a cliff…." The need for transitional services for those leaving school was also highlighted. Currently, physicians stated, needed services are nonexistent: "School offers structure, and then, after school, they are just home watching TV. Need transitional services!"

The third point regarding transitions that garnered the most conversation concerned medication management when moving from health provider to health provider. The single most requested item from a specialist would be a complete medication list for the new patient. Physicians reported that patients arrive with "a ridiculous list of meds that we spend 2 years trying to trim down." The number of *medications that persons with ASD are on was concerning to the physicians in the focus group. No suggestions were offered for remedying this issue.*

Barriers to Care

The barriers to care expressed by the physicians and parents were abundant and worrying to them. The barriers most identified by the specialists and parents were physicians' knowledge of ASD, the expense of services, the need to fight for services, fragmented care, aging out of systems designed for children, and delays in services.

Physicians' knowledge of ASD

Physicians agree that the knowledge base of physicians regarding ASD needs to be increased. There was general agreement among the generalists and specialists that health care providers need training to learn about ASD. Several suggestions were offered as avenues to training which will be discussed in the suggestions section of this report.

Parents were equally adamant in the parent survey regarding the need to train health care providers on basic ASD realities. There were many quotations illustrating parents' desire for better-trained health care providers:

> *"Health professionals with a better understanding of treating and identifying autism…are needed!"*
>
> *"The doctors we have seen have not been a good fit for my son. They don't understand autism, and they don't have the patience an autistic child needs."*

The parent survey results were also telling. The parent survey offers additional insight into parents' experience interacting with the physician's office. Survey results indicate a somewhat favorable view of the parent's experience with the child's physician, but with room for improvement. A majority of parents (54%) report that office staff usually or always help make the visit favorable for the child. Parents also indicated in the survey the desire to have the office visits be more manageable and less overwhelming for their child. The office staff have the ability to affect a child's office visit, and it appears from the survey that some office staff are succeeding, yet others are not.

The parent survey results indicate that the majority trust and feel listened to by the physician, although 39% of the parents reported only somewhat trusting the physician and 9% said that they did not trust the physician. Feeling listened to and getting questions answered are important parts of managing ASD for caregivers. Unfortunately, parents indicate that the majority of the time, they do not have questions answered to their satisfaction (65%).

Parent Survey Responses

During the last 12 months,	n	%
How often were you able to get the care you needed from your child's primary care provider during holidays and weekends?		
Never	9	27
Sometimes	8	24
Usually	6	18
Always	9	27
Child doesn't have a primary health provider[1]	2	6
How many days did your child usually have to wait for an appointment when you child needed care right away?		
Same day	20	57
1 day	9	26
2-7 days	4	12
Have office staff worked with you to make the office visit successful for your child?		
Never	5	14
Sometimes	9	26
Usually	7	20
Always	12	34
How often did your child's provider show interest in your questions and concerns?		
Never	0	0
Sometimes	5	14
Usually	8	23
Always	20	57
How often did you child's provider answer all your questions to your satisfaction?		
Never	1	3
Sometimes	8	24
Usually	13	38
Always	10	29
Do you feel you can trust your child's provider with his/her medical care?		
Yes, definitely	17	52
Yes, somewhat	13	39
No	3	9

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[1] The same two people chose this answer for all the questions

Expense of services

Physicians as well as parents highlighted the need for better reimbursement of needed services for ASD. The physicians in the focus group were touched by the dedication and perseverance of parents to access the needed services for their children. Physicians also lamented the fact that such energy was needed on the part of the parents.

The frustration was evident in the parent quotations in the survey: "I would rather spend the time caring for my children than continue to battle with agencies and companies over every little thing. It shouldn't have to be this hard!!"

Fight for services

Both parents and physicians acknowledge the reality of parents needing to be the care manager, parent, social worker, and health insurance expert. One parent said, "I feel like I have to do it all—all of the coordination on top of working with my child, and that is overwhelming." Physicians spoke with heartfelt respect for the work that parents do for their children with ASD: "To survive as a parent of a child with autism, you have to be an expert and fight for your services and your child."

Fragmented care

A great deal of the focus group conversation revolved around the issue of fragmented care for persons with ASD. Many parents also identified the disconnection among services for their children as a serious impediment to their child's health.

The specialists showed real frustration at being left out of their patients' care:

> *"Autistic patients come with very fractionated care. For example, some may have a group home, a day program, a primary care [physician], neurologist—and yet there is no real communication between them. I [the mental health professional] am left out and don't find out about the coordination of care]meeting until 6 months later! And I am the mental health provider on record."*
>
> *"There isn't a case manager person to tell us what is going on. There is no one to connect us in an organized way."*

Parents are also seeking a better way to connect the care their children receive. The parents feel the effects of the disjointed care and desire better systems to help their children:

> *"I have to do all the coordination of care myself. I don't know what, if any, communication goes on between OT, PT, and the doctor. There is zero communication between the school-based OT, PT, and the doctor. A team approach is needed, which requires me to have an advocate at the IEP meetings. Since doctors don't go to IEP meetings, the coordination all falls back on the parent."*
>
> *"It seems there should be a seamless way to have one database for children on the autism spectrum. All the services are so disconnected.."*
>
> *"More efforts at integrated care…better collaboration between health services, school and community services would be helpful."*

The parent survey results were also powerful. Several referral and care coordination questions were asked. As is found in the national literature, the majority of parents report that their children with ASD access medical, educational, and social services (94%).

As is consistent with the physician feedback regarding their views of coordination of care, the majority of parents (64%) reported that they sometimes or never feel as though they have as much help as they need coordinating their child's care.

Yet the majority of parents report that their child's physician does coordinate care (63%). That still leaves a large percentage of parents who feel that the care is not coordinated.

Parent Survey Responses

	n	%
Did your child use any health related medical, therapies, educational or social services in the last 12 months?		
Yes	34	94
No	2	6
Did you need a referral to see any doctors are receive services?		
Yes	23	68
No	11	32
Was getting referrals a big problem, small problem or not a problem?		
Big Problem	1	4
Not a problem	10	43
Small problem	12	52

Over the past 12 months, how often did you get as much help as you wanted with arranging or coordinating your child's care?	n	%
Never	6	23
Sometimes	14	40
Usually	11	31
Always	4	11
Overall, how satisfied are you with the communication between your child's doctors and other health care providers?		
Very satisfied	8	23
Somewhat satisfied	21	60
Very dissatisfied	3	9
Somewhat dissatisfied	3	9
Do you feel that your child's doctors make sure that services are coordinated to make the best outcomes for your child?		
Yes	22	63
No	13	37

Aging out

The physicians identified the issue of a decline in services when a child leaves the school system or ages out at age 21. The transition from school age, when a child is entitled to some degree of services through the Individuals with Disabilities Education Act, to the adult world, in which eligibility for services is not ensured, presents a daunting learning curve for parents.

One psychiatrist noted two issues that disturbed him. First is the lack of opportunities for persons when they age out, followed by the mental health issues that ensue after aging out. Second, the tendency of physicians to medicate the autistic patient and the response from a knowledgeable psychiatrist causes concern: "What we see is that they age out, and then where do they go? That is when I get them. And they are on a ridiculous list of meds that we spend 2 years trying to trim down. I think I get most referrals from word of mouth. That is how I have learned about autism: from the parents. They are the experts, especially the moms."

Delays in services

The delays in services reported by the physicians and the parents were substantial and consequential. The physicians expressed extreme frustration: "Wait list for job coaches and voc rehab is a big barrier for those higher-functioning folks. I have had one patient that waited for 2 years!"

The parents surveyed were equally displeased by the delay in services experienced by their children. One parent stated: "Please make it easier to find care when he is in crisis other than the emergency room, where he is mixed with adults. We waited 4 weeks for a space that would take him while in crisis."

Results from the parent survey highlighting the experience of many parents are noted below:

- *More than one-third of parents reported difficulties or delays in accessing services because the child was not eligible.*
- *One-half of parents reported difficulties or delays in accessing services because the services were not available in their area.*
- *More than one-third of parents reported difficulties or delays in accessing services due to waiting lists.*

Parent Survey Responses

During the last 12 months,	n	%
Did you have any difficulties or delays getting services for your child because he/she was not eligible for services?		
Yes	13	35
No	24	65
Did you have any difficulties or delays getting services for your child because services were not available in your area?		
Yes	18	49
No	19	51
Did you have any difficulties or delays getting services for your child because there were waiting lists, backlogs, or other problems getting appointments?		
Yes	13	36
No	23	64
How often have you been frustrated in your efforts to get services for your child?		
Never	7	19
Sometimes	19	51
Usually	8	22
Always	3	8

Suggestions

The physicians and the parents proposed various options for addressing many of the issues highlighted in the focus group and survey. Below are the ideas grouped by category.

Improve coordination of care

The physicians reported a desire to be part of the overall treatment plan of their patients with ASD. They recognized that coordinated care would provide more positive outcomes for their patients. The physicians suggested the following idea to be part of their patients plan for better health. "Quarterly treatment planning meetings where everyone would come to us [psychiatrists] would work better than what we are doing."

Parent suggestions for improving coordination included an autism wing (clinic) at hospitals and a database for ASD accessible statewide. Parents repeatedly and emphatically requested that coordination of care be established.

Resource list

All physicians were enthusiastic by the prospect of a resource list dedicated to ASD. The request is that this list be curated, on line, and updated in real time. Some of the facets of the list would be a functionality to search by topic and geographic area. Relevant quotations follow:

> *"A resource list would be great—that was updated, listing programs that have expertise in behavioral management."*
>
> *"Could there be an autism resource list? Is that part of the grant initiative? A website would be wonderful!"*
>
> *"That would be a great role for the Developmental Disabilities Council: putting together a resource list."*
>
> *"An online resource list that could be updated in real time."*
>
> *"The list has to be curated. I need to be able to trust that the referrals are really good. Have the list searchable by county, real time."*

Service line

The physicians discussed how helpful the model of a "service line" is to persons with a particular health issue. The physicians noted how effective the model of a service line has been in neurological oncology and anxiety disorders. The idea is best described in the physicians' own words:

> *"A great model is a phone line: The nurse acts as an outpatient navigator. Neuro-oncology has a dedicated phone line, which is a tiny little patient population. A nurse will answer that phone with any questions related to brain tumors. It is an information hotline funded by the various cancer organizations and grants. A great model! I would definitely use such a hotline for autism."*
>
> *"You could really make an argument for a service line for young adults with developmental disabilities. How do you interface with primary care providers, etc.? We are currently doing this with anxiety disorders at McGeachy hall."*
>
> *"A service line is a treatment protocol and adding to the primary care planning. So we would say if you want to come to our clinic, the case manager has to be on board for quarterly meetings with us."*
>
> *"If there are monies for the idea of having one phone number and one nurse, if you have grant money that is about improving the care of patients with autism…if you could have a nurse be picking up the phone who could look into 'How does that person get voc rehab? This person's parents are 75, and they are going to need a group home,' that would be an amazing resource."*

Clinic

Another idea noted by the physicians and the parents is a physical "clinic" within the hospital walls, One physician stated: "If you were to set up a 'clinic' with one physician and mid-level experts, then you could address multiple issues at the same time, like spina bifida clinic, where you have the nurse expert." Several parents had similar thoughts: "If I have cancer, I can go to the cancer wing and get solid treatment…. Why doesn't every major hospital have an autism wing where behavior, diet, ABA, therapy, OT, speech, meds is established?"

Training

Several options for presenting training to health care providers were discussed, with varying degrees of enthusiasm. A conference for allied health professionals as well as other health care providers was suggested and enthusiastically accepted. There was discussion regarding providing breakout sessions by geographic area and promoting real discussions to improve systems for persons with ASD. An identified drawback to the conference is the challenge to schedule time away from a medical practice. An additional recommendation regarding the conference was to act on the energy generated by the conference by launching an ASD-focused website and listserv for practitioners working with ASD clients.

Another idea received positively by all physicians in attendance was grand rounds. One physician stated, "Grand rounds would also be great. It is great to have a whole department get the information instead of a select few. "

Many of the physicians supported the idea of a list serve. The physicians stated the desire for additional support and resources regarding ASD and the listserv as a suggestion to meet that need. The following quotes represent the physician's views:

> *"I would like to see a listserv where I could ask for ideas about scenarios. This is the first time I have met you guys, and I would like to keep in touch. We had something in Epilepsy Society, and that worked well."*
>
> *"Listserves are wonderful resources for tricky situations—could be multispecialty—should be statewide, not just the MMC system."*

The idea of an ASD webinar for training was not supported by the physicians. The physicians stated that they have good intentions to attend webinars but, in the end, do not attend them due to lack of time.

Environmental changes

Many parents noted that waiting rooms in health providers' offices are a source of stress and anxiety for the person with ASD as well as the parents. Suggestions from the parents are as follows: "I wish there were separate areas for kiddos with autism/special needs so we didn't have to sit in waiting rooms."

Conclusions

The conversations with physicians and the survey with parents provided insight and understanding for some of the health care challenges and possible solutions for persons with ASD in Maine.

The findings from the conversations with physicians and the survey with parents are consistent with findings in the national literature. Regarding transition, the National Longitudinal Transition Study-2 (NLTS2)[iv] *concluded, "Transition planning and implementation is falling short of what the federal government intended for many with ASD." A sentiment supported by the physicians as well as the parents.*

The status of accessing services after "aging out" has been investigated, and the findings are distressing and supported by the physicians and parents in this sample. Researchers again turned to the NLTS2 data to examine the post high school use of services among young adults with an ASD[v] *speech therapy is a common service accessed by persons with ASD. In fact, the researchers found that 74.6% of high school students had received speech therapy. The percentage of young adults receiving speech therapy dropped to 9.1% after they left school. An important note is that 20% of the sample were nonverbal and thus would likely benefit from speech therapy.*

Dedicated and thoughtful parents and physicians offered many suggestions during the conversations and survey. Many people took the time to give their opinions with the thought that they would help improve care for persons with ASD. It is apparent that there are improvements that are achievable and that physicians are ready to listen.

After analyzing the results of Altarum Institute's parent survey, it was decided that Autism Implementation Grant (AIG) funds would be utilized for a project aimed at determining if any disparities exist between the health care provided for individuals with ASD as compared to the general population. AIG contracted with a consultant who performed a thorough literature review and conducted extensive interviews with 78 family members of children and youth with ASD and 21 adults with ASD. Survey participants represent a diverse geographic, economic, age, and gender sample. The diagnosis range spread across all three ASD categories (Autism, Asperger's and PDD-NOS) and many identified as having multiple diagnoses. The sample included parents with multiple children, parents who are guardians, foster parents, and parents who were homeless.

The Center for Community Inclusion and Disability Studies, Maine's member of the Association of University Centers on Disabilities (AUCD), is currently analyzing the data gathered from these interviews.

Goal 3: Expand the capacity of families to advocate for and ensure appropriate services are provided.

☑ ***Objective 3.1 By August 31, 2013, more than 200 families of children with ASDs will have been trained regarding he "medical home" model of care, and how to interact with medical providers and advocate for their children's needs.*** *(Italic portions are reports from Altarum Institute)*

AIG contracted with the Maine Parent Federation (MPF) to develop and present a curriculum on medical homes for families of children with ASD. MPF worked with the Autism Society of Maine (ASM) to develop a curriculum, and once developed ASM also presented the material to families.

Both ASM and MPF found challenges attracting groups to host and families to attend the presentations. Both reported that families do not seem to be attending as much training as they did 10 years ago. MPF reported that they believe that "families are busy raising their children and working to keep a roof over their heads and food on the table. This does not mean that information is not important to them; it means that they have busy lives and are accessing the information via the internet."

The curriculum was made accessible to families using three distinct strategies; face-to-face presentations, internet webinar modules, and literature dissemination.

- Face-To-Face Trainings: Both ASM and MPF conducted 17 face-to-face trainings where 130 families received the information.
- Internet Webinar Modules: The training has been live on the MPF since the spring of 2013. MPF has had some technical difficulties and, unfortunately, were unable to give an accurate count regarding how many individuals viewed the presentations. They did send an email and link to the presentations to all the parent organizations who are part of the MAFO (Maine Alliance of Family Organizations) requesting that they share the information with their constituents. The modules can be found at http://www.startingpointsforme.org/content/medical-home-training .
- Literature Dissemination: ASM disseminated information at over 10 resource fairs/conferences and 9 presentations reaching as many as 475 members of the public.

Below is Altarum Institute's evaluation of the face-to-face trainings.

As part of the Maine Autism Spectrum Disorders Systems Development Initiative, Altarum worked with the Maine Parent Federation to conduct baseline and follow-up surveys to assess the effectiveness of the medical home trainings they conducted for parents of children with ASDs. This memo presents the results of these surveys.

Pre-Workshop Baseline Survey

Prior to the training, the workshop participants were asked to complete a brief survey that asked them to rate their own level of knowledge on four aspects of the medical home: the concept of the medical home, the components of the medical home, the implications of the medical home for children with ASDs, and how to select a doctor that would best meet their child's needs. In addition, respondents were asked to describe in their own words what the term "medical home" meant to them, and what additional information would be most useful about the medical home.

A total of 43 participants completed this survey. Table 1 below shows the results of the knowledge rating questions described above.

Table 1.

Pre-Workshop Knowledge Ratings (N=43)

	Very knowledgeable	Knowledgeable	Familiar	Have little knowledge
The concept of the medical home	2	11	15	15
The components of the medical home	0	8	14	21
The implications of the medical home for children with ASDs	2	5	14	22
How to select a doctor that will meet the child's needs	3	15	12	13

As Table 1 shows, prior to the workshop, parents were not confident in their knowledge of the medical home or what it meant for their children. Rating "very knowledgeable" as 4 and "have little knowledge" as 1, the mean score for understanding of the concept of the medical home was 2.0, and the mean for knowledge of the components of the medical home was 1.7. For understanding of the implications of the medical home for children with ASDs, the mean rating was 1.7 as well. The mean rating for how to select an appropriate doctor was slightly higher, at 2.2. Thus, the workshop participants' ratings of their knowledge and comfort with the medical home concept and what it might mean for their families hovered around the "familiar" level.

In some cases, however, participants' actual understanding of this concept was greater than they thought, although many did not have an accurate understanding of the medical home concept. Four respondents left this question blank, 5 indicated that they had never heard the term or had no idea what it meant, and 2 gave general answers that did not reflect the components of the medical home. Eight *thought it referred to home-based medical services or hospice care, and an additional 5 gave definitions related to the provision of services in the home as an extension of office-based care. The remaining 19 gave definitions that reflected some component of the MCHB's definition of the medical home, primarily care coordination or family-centeredness. These are displayed in Table 2 below.*

Table 2.

Parents' Definitions of the Medical Home (N=19)

Keeping the child in home with medical support. Family first, family driven. Parents heard and part of the team	Working with family and providers to receive the best care for the child
All the needed components in one place and care is coordinated in that medical home	Where all the needs get met- all encompassed
That the medical practitioners are part of a group who looks at the child and family's needs. Other group members would include community case managers, education, therapists, and providers.	An all around person who is knowledgeable in various areas of my child's well being.
A service which is compassionate, takes into account all facets of care-focus on a family-centered, participant-driven, culturally competent- focus on strengths	Completely a guess: services model providing all a family may/will need to best meet all the needs, including medical within their family culture?? All inclusive circle around the family and child with ASDs.
Family-centered, comprehensive, coordinated care that includes validation of family input and follow-up with services outside of primary care	A cluster of physicians, agency, state depts, etc that make a one-stop site for parents of CSHCN--and can be utilized by parents of typically developing children as well--they may need a service in the future.
Being able to get all your medical needs met through one central location	Medical home to me means: having the supports for your child's needs be taken care of and managed at one place-having someone oversee your child's care
That the most appropriate doctor may not always be the PCP. You take the child to where its most comfortable, not where many	One location where a variety of services or challenges can be addressed or met

think you should	
Co-operation between providers, educator, specialists and parents. Coordinated care. Care coordination in hospitals.	A doctor's office that provides support for families for most medical needs. The doctor is aware of all components of the person's medical treatments.
The team I assemble around my son's and my needs, mediated by me. Who I choose is up to me based on how well these professionals respond to our needs.	A primary physician or practice that is familiar with child and family
A way of communicating a child's needs to medical providers; advocating	

Regarding the participants' need for additional information about the medical home, all but 3of the respondents answered the question and expressed a desire for more information about the medical home in general, what it can do for their families, how children might qualify for such a service, and how it would apply in a rural area where the choice of providers is limited.

Post-Workshop Follow-up Survey

After the workshop, participants were sent a link to a brief online survey that asked several factual questions about the medical home and its components, as well as two questions about how participants had used the information they had received at the workshops. Forty-two participants completed this survey.

On each of the two multiple-choice knowledge questions, regarding the definition of the medical home and what it means for children with ASDs, 41 respondents answered correctly that the medical home is "A source of health care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective," and that, for a child with ASD, having a medical home means that the family has a doctor who is familiar with the child and knows what his or her needs are; the doctors' office environment meets the child's sensory needs; and the doctors' office is familiar with the child's IEP and what it contains, and coordinates the various sources of services that the child uses.

Respondents were asked to describe, in a sentence or two, the major components of the medical home. Seven respondents left this question blank. For those who responded, Table 3 below shows the number of responses that mentioned each element of the MCHB and AAP's definition of the components of the medical home--accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

Table 3. **Components of the Medical Home (N=35)**	
Accessible	5
Family-Centered	14
Continuous	8
Comprehensive	9
Coordinated	13
Compassionate	9
Culturally Effective	0

Some examples of respondents' definitions are presented below. Some respondents repeated some or all of the components in the MCHB definition:

- *Accessible, continuous, comprehensive, family-centered, coordinated, compassionate, able to meet both the child and the parents needs. They are able to communicate well with all providers involved in the child's life.*
- *Continuous health care services that are accessible, comprehensive, and effective for families to meet their health care needs.*
- *A medical home is family centered and compassionate.*
- *A comprehensive system of care that is accessible.*
- *Coordination of services to meet medical needs of the child and family, a way of doing so in a continuous way with compassion.*

Others rephrased the major components that were most important to them, using their own words:

- *Health care that coordinated and sensitive to the patient and family needs and stressors. The coordination of records and appointments being done as much by the professionals involved as possible, to lift extra burdens from the family.*
- *Comfort, care, and compassion I feel are major components of patient care. These are what most people look for and the rest will come together.*
- *The major components of the medical home model are providing patients with consistent care with familiar providers who are knowledgeable about the patient's needs, diagnosis, and care plan.*

Others interpreted the "components" of the medical home as the participants in the system of care or elements of high-quality care:

- *The major components of the Medical Home include the child and family, any medical organizations (doctors, specialists, etc) and any other service organizations helping the child or family.*
- *Families, health care practices, government agencies, educational agencies, PCP, professional organizations.*
- *Being prepared, naming your medical providers, them being understanding of the patient, staying on top of medical problems, and working with medical providers. It is a caring, understanding medical facility.*

Only one respondent gave a definition that focused on the child's home rather than his or her medical care ("A safe home for a child with severe disabilities and needs help with multiple health situations"), an error that was common in the pre-workshop surveys.

When asked about the strategies they have used to prepare and help their children with visits to the doctor, 17 reported that they had not been to the doctor with their child since the workshop, 4 left the question blank, and one reported that she did not have a child with ASD. Of the remaining 20, 15 checked off "preparation," 10 "comforters/distractions," 8 "professional support," 4 "rewards," 4 "visual supports," and 3 "stories." Many respondents checked more than one strategy.

The final question asked what participants had done to help their providers to be a better medical home. Again, 20 respondents indicated that this was not applicable as their child had not been to the doctor since the workshop, and 5 left the question blank. The remaining respondents checked the following responses:

- *Share information with the provider about my child's changing needs and development (11)*
- *Brought a list of questions to the visit (10)*
- *Asked for more information or explanation (8)*
- *Informed the provider that we would need extra time (3)*

In addition, one respondent wrote in "coached my son to do these things as he is now an adult."

Discussion

The pre- and post-workshop surveys showed both that the training in the medical home was needed and that it was successful. While parents did seem to know more about the medical home than they thought they did, their lack of confidence in their knowledge may have undermined their ability to work with their providers to get the best care possible for their children. After the workshop, those who completed the post-workshop follow-up survey were much more knowledgeable about the medical home and many were able to translate this knowledge into action on behalf of their children.

These surveys were brief and did not explore in depth the many aspects of the medical home addressed in the training workshops. Nonetheless, these findings demonstrate the promise of training in the medical home to inform and empower parents to advocate for better primary care for their children.

☑ Objective 3.2 By August 31, 2013 parent organizations will have expanded their capacity to provide information related to screening, referral, diagnosis and treatment to families of Maine

The AIG contracted the Autism Society of Maine (ASM) to collaborate with MPF and develop new webpages for their website to provide information about "medical homes" for children and the benefits of care management for children with autism spectrum disorders provided through a medical home. Further, they enhanced their website to include appropriate links about medical homes, family organizations, and other community resources to assist families and individuals with Autism Spectrum disorders with their search in finding services and supports. The website can be found at http://www.asmonline.org/medical_home_model.asp

Goal 4: Conduct pilot studies to evaluate the effectiveness of new protocols for early identification and referral to early intervention services, and for improving access to medical homes for children and youth with ASDs.

☑ ***Objective 4.1 Conduct pilot studies in multiple locations with developmental pediatricians and Child Developmental Services (CDS) sites to evaluate current processes for referral and evaluation, and field test algorithm developed to streamline early identification and access to early intervention services.*** *(Italic portions are reports from Altarum Institute)*

As the population of children diagnosed with Autism Spectrum Disorders (ASDs) increases, the systems of care that serve these children—including early intervention programs, specialty medical care, special education, and primary medical care—are becoming increasingly strained. To address the issues of fragmentation and lack of coordination in these systems, the Maine Developmental Disabilities Council, in partnership with the Maine Department of Health and Human Services, has received a three-year grant from the Federal Maternal and Child Health Bureau to conduct a variety of systems development efforts in the state.

One of these efforts is a pilot project to improve the system of identification, screening, referral, and evaluation of children for ASDs. Two sites were chosen for this pilot: Cumberland County and Bangor. These sites were chosen by the Department of Education, the lead agency for IDEA, because of specific circumstances in each location that appeared to impede coordination, communication, and smooth transitions between specialty medical care and the relevant Child Development Services offices.

Altarum Institute was contracted as part of the grant to provide local evaluation services to the Maine DD Council. As part of this evaluation, Altarum conducted key informant interviews of the specialty medical providers and CDS offices in both pilot sites, and as far as was possible, analyzed data collected by the pilot sites on the children they served. This report presents our findings for each of the sites separately, concluding with a discussion of the lessons learned and prospects for sustainability of the two sites and expansion to other counties in Maine.

A. Bangor

The Bangor site was selected for the pilot due to well-known and longstanding hostility and mistrust between the CDS agency and Eastern Maine Medical Center's (EMMC) Developmental Pediatrics department. Before the pilot began, under two previous CDS Directors, communication was episodic and circuitous, and parents had a poor impression of their ability to access services through CDS. The hiring of a new Director helped to address these problems. However, the history between the two agencies required that a systematic and organized effort be implemented to restructure their referral and communications systems.

The goal of the pilot was to improve communication between EMMC and CDS around the identification and provision of services for children with ASDs. To do this, a system was established for referral, screening, evaluation, and care coordination, as described below.

***Referral and Evaluation**. Primary care providers, who are the main source of referrals for children who may have ASDs, are asked to refer to both CDS and EMMC in parallel. Upon referral to EMMC, the parent is given a questionnaire to determine whether the family has been referred to or is already* *involved with CDS, and they are asked to sign a release to share information with CDS. EMMC also determines whether a CDS assessment has already been scheduled, and a multidisciplinary team evaluation is set up as well.*

When a child is referred to CDS, the agency conducts a telephone screening and sends a written notice and consent form to the family. CDS will also offer the family a home visit where they will discuss the forms and evaluations. CDS will conduct the Batelle evaluation, generally within the timeframes established under IDEA of 45 days for children aged 3-5 and 60 days for children under age 3. While CDS does not refer directly to EMMC, since there is no contract between the two agencies, they will recommend a medical evaluation for any medical conditions that are present. CDS does ask families whether their child is being seen at EMMC, and they have found that they have to use very specific language, as families are not always fully aware of the relationships between the various providers in the community.

In the case of older children who may be enrolled in Part B (those aged 3-5), CDS is generally already involved, so EMMC will request Individual Education Plans (IEPs) or Individual Family Service Plans (IFSPs) from the CDS agency, so as not to duplicate any services. The child will be seen at EMMC by the developmental/behavioral pediatrician and the clinical psychologist, so as to look at cognitive and medical issues jointly. They then provide recommendations, which may differ from the IEP or IFSP developed by CDS.

The families of children enrolled in MaineCare who have developmental needs but who do not meet the eligibility criteria for CDS receive a letter explaining the decision and recommending that they contact their physician to access any services they might need. Children with private insurance do not receive this letter, but are given this information verbally.

Enrollment in the Pilot

Eligible children are enrolled in the pilot program and their parents sign a consent form. EMMC then calls the CDS case manager to discuss the IEP and compare its services with those recommended by EMMC. Services funded through CDS and Section 28 are described as "seamless;" if, for example, CDS authorizes 15 hours of Applied Behavioral Analysis, but 30 hours are needed, Section 28 funds are used for the additional 15 hours.

Ongoing Care Coordination

Throughout the pilot, monthly meetings were conducted with the relevant case managers to discuss issues and assure that everyone is aware of decisions that have been made. Prior to the pilot there was no positive communication between EMMC and CDS and there was much distrust between the two agencies. EMMC staff do not attend IEP/IFSP meetings, so these team meetings are the best way to share information. In addition, children with ASDs generally have a community case manager who serves as a "communication bridge" between the provider agencies. Direct communication between EMMC and CDS over the course of the pilot has been approximately monthly over the course of the pilot. Both CDS and EMMC report increased and improved communication and trust as a result of the regular meetings.

CDS provides quarterly progress reports to everyone named on the child's care plan and to the family, and CDS meets with the family every six months to review progress as well. On the EMMC side, information on the child from CDS is included in the electronic medical record, which is shared with most of EMMC's primary care practices. However, the original plan to establish a single care plan that *documents both educational and medical services did not come to fruition, so the care coordination at EMMC is conducted by the physician and services documented in the medical record.*

The plan for the pilot was to enroll 30 children between February and August 2012. However, it was hoped that the permanent effect of the pilot would be to improve communication so that sharing information between EMMC and CDS becomes common and routine, and to help CDS and the community case managers to understand the need for all agencies to work together. Both CDS and EMMC report that significant improvements have been made in regards to trust and communication. EMMC and CDS are hopeful and inspired to continue open communication. The groundwork has been laid and both EMMC and CDS will work to continue improved communication. Specifically, the pilot has demonstrated improvements in service planning, care coordination, and service delivery, as described below.

Service planning

EMMC documented valuable information as a result of the pilot program. Data was collected at the commencement of the pilot project. No data were collected prior to the pilot, so it is not possible to compare these finding to the timelines prior to the pilot. EMMC staff noted that an issue with the data is the denominator does not reflect all children screened, only those children with a diagnoses of autism, so it does not illustrate the volume of screenings conducted by EMMC.

Table 2 shows the average number of days between the following milestones, for the population of CDS-referred children during the pilot. The milestones are:

- *The date of referral to the date the packet was received by EMMC*
- *The date of referral to the date of the first visit*
- *The date the packet was received by EMMC to the date of the first visit*
- *The date of the first visit to the date of the diagnosis visit*
- *The date of the referral to the date of the diagnosis visit*

A number of factors may influence the timing of some of the milestones; the receipt of the packet of forms depends on the amount of time the family takes to complete the forms, and the dates of the initial appointment and diagnosis depend on the family keeping the appointments after they are made. According to EMMC, there are two important lessons to be learned from the data: first, that EMMC has does not have sufficient staff capacity to serve the number of potential patients. As a result, EMMC has posted a job opening for a Developmental Pediatrician. EMMC anticipates the position to remain unfilled for a year or two due to the fact that physicians generally do not want to relocate to the Bangor area. The second lesson is the issue of inadequate referrals for Autism screening. EMMC believes that if providers would conduct a complete screen, including the MCHAT-2, that the number of positive referrals for autism would increase and the number of inappropriate referrals would decrease.

Thirty children enrolled in the pilot, 24 with a diagnosis of autism, 4 with a diagnosis of PDD-NOS and 2 with a diagnosis of Aspergers disorder. As the table shows, the timelines for all milestones are significantly longer than is desired by EMMC. The data reiterated to EMMC the insufficient number of physicians on staff for the number of autism referrals. Improving the referral process to decrease the number of inappropriate referrals would lessen the screening load of EMMC. One suggestion identified was for referring physicians to be more specific regarding the perceived reason for an autism referral.

A quality improvement initiative may be effective in training referring physicians on what behaviors and milestones warrant a referral for evaluation to EMMC

Table 2.
Average Number of Days Between Milestones: EMMC

Diagnosis type	**Referral to receipt of packet**	**Referral to first visit**	**Receipt of packet to first visit**	**First visit to Dx visit**	**Referral to Dx visit**
Autism(n=24)	50	110	85	0	132
Asperger's (n=2)	31	118	87	23	118
PDD-NOS (n=4)	24	132	108	0	132
All Children <3 (n=15)	57	89	51	36	123
Children ≥3 (n=15)	34	138	119	0	138
All Children (n=30)	44	113	89	36	131

Care coordination

Several case managers may be involved with each child, including the CDS case manager, a community case manager, and a social worker. If children are enrolled in MaineCare, they can receive case management, but for children with private insurance, CDS case management is the only option. Under the pilot, of the 16 children referred through EMMC in Penobscot County (15 of whom had a diagnosis of autism), and one referral from Piscataquis county, all 17 were referred for community case management after being evaluated by EMMC. There were 12 referrals to CDS by EMMC.

Service delivery

Table 3 shows the number of children for whom each service was recommended for those who were referred by the Autism Case Manager. The primary services, to which at least half of the children in the pilot were referred, include speech therapy, occupational therapy, community case management, and in-home supports. Unfortunately, no information is available with which to compare these findings to referral patterns before the implementation of the pilot.

Providers at EMMC have noted a number of specific benefits of the new system, which are likely to continue beyond the life of the pilot. Most important is the increased effective communication and trust between EMMC and CDS. Second, streamlining the process of completing documentation and making appointments has been a benefit to children and their families. In addition, when the referral to EMMC is made by CDS, the family is told that this referral is being made because of a concern about autism spectrum disorders. CDS also takes care to discuss the difference between medical and educational services for autism and to explain the limits of what each agency can provide, thus preventing frustration and misunderstanding for parents in coordinating services for their child. This allows the parents to come to the initial appointment more prepared and informed than they otherwise would.

Providers have also noted specific areas in which service delivery has improved under the pilot. EMMC providers and CDS have participated in monthly face-to face-meetings to improve the coordination of care, allowing EMMC and CDS to make service recommendations at these meetings. CDS does not have a referral contract with EMMC and thus does not refer clients for autism evaluation. CDS will refer clients to EMMC for medical services.

Table 3
Services Recommended for Children in the EMMC Pilot

Recommended Service	Number referred
Community Case Manager	17
CDS Two Rivers	12
Developmental Therapy	7
In-home supports (section 28 or 65)	15
In-home supports MaineCare	2
Occupational Therapy	17
Specialized Preschool	9
Inclusive Preschool	1
Speech Therapy	20

B. Cumberland County

Cumberland County was chosen as a pilot site because of the contractual relationship between the county's CDS office and the specialty physicians' practice at Maine Medical Partners (MMP). Communication and information-sharing between the two agencies has always functioned well, but the existence of the contract may influence the physicians' recommendations. Therefore, the goal of the pilot was to document what the providers were already doing and to identify areas where service delivery and coordination could be improved. The pilot did serve to streamline the referral, screening, and evaluation process, as described below.

Referral and screening

When children are referred to CDS, the agency sends home the required evaluation and consent forms and schedules the initial screening visit after the paperwork has been returned. This is a significant improvement from the previous process, in which MMP would send the paperwork home with the family and it was frequently not returned. Now, the referral is not made to MMP until the forms are in hand, which speeds the process considerably, making it possible to meet the mandated timelines more easily.

An initial evaluation is conducted by CDS, which includes the MCHAT and other testing. When ASDs are suspected, a referral is made to MMP; children with other diagnoses, including ADD/ADHD or emotional disturbance, are seen by a psychiatric specialist at CDS. This has helped to reduce both caseloads and waiting times at both CDS and MMP, and the developmental/behavioral pediatricians at MMP now hold spots for children coming in through CDS. (While having a policy of limiting referrals to children who are suspected of having ASDs has been helpful, in fact, not all children referred to MMP end up with an ASD diagnosis.)

Service Planning

When a child is referred to MMP, appointments are made at one time for the first three visits—an initial interview, testing, and follow-up—followed by a team meeting, which includes the physician, CDS, the parent, and any therapists or other team members who need to be involved. At this meeting, the IEP or IFSP is developed. While the focus of the meeting is CDS-funded educational services, the need for additional services that may be covered under Section 28 is discussed as well.

The goal of this new system is to more consistently meet the IDEA standards for timeliness of evaluation (60 days for children under 3 and 45 days for children 3 and over). The database documents the improvements in the timeliness of referrals and service planning since the introduction of the pilot.

However, it should be noted that the data on pre-pilot milestones was assembled after the fact, from paper medical records that may have been incomplete. Therefore, the data on the 19 baseline cases should be interpreted with caution.

Table 4 shows the average number of days between the following milestones, for three populations: CDS-referred children prior to the pilot; CDS-referred children during the pilot; and children referred from other sources (generally their primary care providers) from counties other than Cumberland during the pilot period. The milestones are:

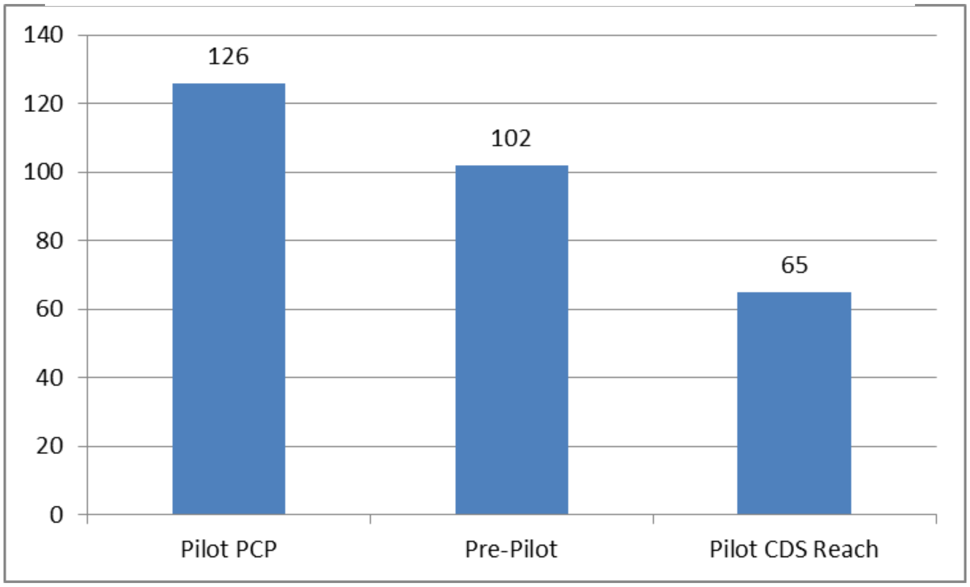
- *The date of referral to the date the packet was received by MMP*
- *The date of referral to the date of the first visit*
- *The date the packet was received by MMP to the date of the first visit*
- *The date of the first visit to the date of the diagnosis visit*
- *The date of the referral to the date of the diagnosis visit*

A number of factors may influence the timing of some of the milestones; the receipt of the packet of forms depends on the amount of time the family takes to complete the forms, and the dates of the initial appointment and diagnosis depend on the family keeping the appointments after they are made. The most meaningful statistic, from the perspective of MMP, is the time from the referral to the date of diagnosis, as this represents the time that the family waited, after being referred to MMP, for concrete information about their child's development. As the table shows, the process for filling out forms and getting the packet to MMP is considerably more timely under the pilot and the contractual agreement between CDS Reach and MMP than either before the pilot or for children in other counties. Likewise, the first visit and the diagnosis visit happen considerably sooner for children referred by CDS Reach, leading to a final wait time of about two months from referral to diagnosis for CDS Reach clients, compared to 83 days for those referred by their PCPs.

Table 4.
Average Number of Days Between Milestones: MMP

	Referral to receipt of packet	**Referral to first visit**	**Receipt of packet to first visit**	**First visit to Dx visit**	**Referral to Dx visit**
Pre-pilot N=19	39	51	16	50	**102**
Pilot, CDS Reach N=83	12	42	32	22	**65**
Pilot, PCP referral N=29	39	95	55	30	**126**

Reduced Process Between Referral To Diagnosis By Over A Month!



Care coordination

Several case managers may be involved with each child, including the CDS case manager, a community case manager, and a social worker. If children are enrolled in MaineCare, they can receive case management in addition to the services provided by CDS, but for those who are not eligible for MaineCare, CDS case management is the only option. Under the pilot, of the 20 children referred through CDS Reach in Cumberland County (17 of whom had a diagnosis of autism), all 20 were referred for community case management after being evaluated by MMP.

Service Delivery
Table 5 shows the number of children for whom each service was recommended for those who were referred to MMP through CDS Reach (in Cumberland County) and via their PCPs (primarily in other counties). For every service, the number of children receiving the service increased after evaluation by MMP, and for many of the children already receiving the service, the amount authorized increased. This was true for both children referred through the pilot (CDS Reach) and those referred through their PCPs.

Providers at MMP have noted a number of specific benefits of the new system, which are likely to be sustainable. First, as has been noted, streamlining the process of completing documentation and making appointments has speeded the process of evaluation and diagnosis considerably, to the benefit of children and their families. In addition, when the referral to MMP is made by CDS, the family is told that this referral is being made because of a concern about autism spectrum disorders. This allows the parents to come to the initial appointment more prepared and informed than they otherwise would. In addition, because families understand why they are being referred to MMP, they feel more comfortable committing to 3 appointments at once, and MMP experiences fewer no-shows.

Table 5.
Services Recommended Under CDS Pilot in Cumberland County

Recommended Service	**CDS Reach Referral**		**PCP Referral**	
	Pre-MMP	***Post-MMP***	***Pre-MMP***	***Post-MMP***
Community Case Manager	-	20	-	7
Preschool Consultation	3	7	-	1
Developmental Therapy-home based	19	27	3*	6
ABA In-home Services	-	-	-	5
In-home supports	-	3	2	4
Interpreting	1	1	-	-
MaineCare/Katie Beckett	-	7		
SSI	-	15 discussed	-	-
Occupational Therapy	18	49	7	12
Physical Therapy	5	10	2	4
Service Coordination	2	2	-	-
Specialized Preschool	21	53	11	16
Specially Designed Instruction	19	22	1	3
Speech Therapy	41	70	11	17
Social Skills Group	-	-	-	1
Transportation	1	1*	-	-

*amount of service authorized increased for those who were receiving it

Providers have also noted specific areas in which service delivery has improved under the pilot (and which are better for children referred through CDS Reach than other sources). Clinical slots are reserved for evaluations for CDS Reach clients (although sometimes these evaluation slots are used for follow-up appointments, which is unnecessary), and MMP providers are included on the care team and *are involved in IEP/IFSP meetings for these children, improving the coordination of their care and allowing them to make their service recommendations at these meetings. In contrast, when children are referred by their PCPs, records must be requested from the PCPs' offices, and coordination and communication are minimal. For this reason, MMP providers have learned to be especially specific in their service recommendations for children coming from counties other than Cumberland, as the providers have less opportunity to advocate for their recommendations. Finally, MMP providers noted that CDS Reach is authorizing more services for children with ASDs and these services are closer to adhering to the standard of care for these children since they have begun collaborating more closely with MMP.*

One area of concern for the providers at both MMP and EMMC is CDS's reliance on the Primary Service Provider (PSP) Model of in-home developmental therapy for children under age 3. It is unclear exactly how many children in the two sites receive services through the PSP model, but it is evident from the database that at least 14 children under age 3 in Cumberland County, along with 7 children in Penobscot and Piscataquis, receive PSP services. This model relies on a "primary coach" to work with the family, has the benefits of integrating therapy services into the family's home life and routines and is focused on meeting the family's goals. However, by relying on one primary therapist, this model may lose the multidisciplinary focus that is a requirement of IDEA and is necessary to address the multiple domains affected in children with ASDs. In addition, the evidence base for the effectiveness of this model is limited. MMP providers suggest that guidelines be developed and applied to assure that regular team meetings occur and the multidisciplinary consulting team is fully engaged with children who receive services through this model.

Based on their experience with the pilot in Cumberland County and the contract with CDS, MMP providers made a number of recommendations for improvements to the system more widely. This pilot could provide a model for relationships between CDS sites and specialty physicians throughout the state. Rather than referring children from far-off counties to MMP, CDS agencies could be encouraged to develop contractual relationships and referral systems, along Cumberland County's model, with local psychologists and developmental/behavioral physicians. In addition, CDS agencies throughout the state need education and training in autism spectrum disorders and the use of the MCHAT for screening, as CDS Reach does. (This has happened, to some extent, through the ASD Systems Development initiative.)

C. Conclusions and Lessons Learned

Overall, the pilots succeeded in improving communication and the timeliness of the screening and referral process in both sites. While the pilot addressed specific areas of concern in each site, the next step is to identify elements of the pilot that may be transferable to other counties, so as to improve systems of care for children with ASDs statewide.

While the two pilot counties each addressed their own challenges through their pilot projects, it is likely that the process of planning the pilot—including meeting to discuss the process; making explicit the expectations of all parties regarding documentation, communication, and timelines; and coming to agreement about ongoing communication and information-sharing—were as useful in improving the system as the pilot project itself. Thus, one recommendation for expansion of the pilot is to conduct meetings in each county with the CDS agencies and providers of specialty care to walk through this process and identify areas where the system could be improved or streamlined. These meetings, which could be organized and facilitated by the Maine Developmental Disabilities Council, would cover the major issues addressed by the pilots, including the process of facilitating referrals to specialty providers *and the information needed to accompany these referrals; gathering documentation from parents; the expected timelines for appointments and evaluations; participation in IEP/IFSP meetings; service authorization; and ongoing communication, record-sharing, and case meetings. It is likely that each area will have its own process and needs in each of these areas, as did the two pilot counties. However, the mere process of discussing the process, identifying areas for improvement, and making each party's needs and expectations explicit is likely to contribute to an improved system.*

Another area for further exploration is replication of the contractual arrangement between CDS and the specialty providers in Cumberland County. While this arrangement may not be desirable or feasible in all areas, it may be useful to discuss with other county CDS agencies and specialty providers the specific advantages of the contract, including ease of information-sharing, the ability to reserve appointment times, and direct referrals for evaluation by specialists when ASDs are suspected.

The pilot has also highlighted areas where room remains for improvement. Both sites noted that the major constraint, and the driver of timeline challenges, was the capacity of the specialty providers. Both practices have large backlogs, and EMMC is currently advertising for a new developmental/behavioral pediatrician. Ultimately, the capacity of the specialists is a key determinant of the timeliness of the referral and evaluation process.

The pilot also highlighted the need for better initial screening on the part of primary care providers, who are, in most counties, the source of referrals to specialist providers. An initial MCHAT would provide a sense of the severity of developmental delays and the likelihood of an ASD diagnosis (and if primary care providers were able to assess children's development using the MCHAT-2, even more information would be available). In addition, the referral document itself could provide more information to providers that allowed them to triage and prioritize referred children for evaluation.

The final element of the pilot, which is not likely to be sustained, is the use of a database to track the milestones in the referral, evaluation, and diagnosis process. In both sites, providers felt the database to be a burden that did not improve their systems or practices, although it was necessary in the pilot phase to document the functioning of the system. However, in the absence of the database, it remains to be seen whether improvements in timeliness will continue, and whether some form of oversight is necessary to assure providers' adherence to target timelines.

Overall, the pilots demonstrated that small process changes can improve coordination and communication between CDS and specialty providers, both essential elements of the system of care for children with ASDs. The ongoing challenge will be come in sustaining these improvements in the pilot sites and replicating them in the rest of Maine's counties.

☑ Objective 4.2 Conduct a pilot study with two medical practices involved in CHIPRA medical home study to model enhanced care coordination services for families with children with ASDs. (*Italic portions are reports from Altarum Institute*)

The medical home pilot was implemented at Husson Pediatrics in Bangor a large general pediatric practice in central Maine. The practice has approximately 7,500 patients with a larger percentage of patients having an ASD than most family practices. The AIG was unable to find a comparison site. The first candidate, Maine Medical Center in Portland Maine, opted not to participate because they lacked expertise in ASD. The second candidate, Southern Maine Medical Center in York County Maine opted not to participate due to time constraints.

The pilot consisted of the use of a care coordinator who worked with families, usually by phone, to address care coordination needs. The pilot began enrolling children in June 2012 and continued through August 2013. The goal of the pilot was to evaluate the effectiveness of coordination of services for children with ASD; to identify barriers, if any, for effective intervention for these children; and to generate possible solutions to these barriers as they arise to improve services and outcomes for children with ASDs.

The care coordinator, Rochelle Harriman, telephones the family within 24 hours of the receipt of a referral to enroll the child in the pilot and begin the care coordination process. She then continues to interact with the family over time, reporting that families generally need care coordination at three critical times:

- ***When they are initially referred for evaluations by the PCP because of concerns regarding developmental delays***

  The care manager can help parents better understand the process of diagnosis and what they can expect at each step. This eases anxiety and provides the parents with information they will need for informed decisions along the way. Parents have an incredible amount of stress around the possibility of autism as a diagnosis and the delays they see in their child. Knowledge from the care manager is power and relieves anxiety.

- ***After the diagnosis is received and they need guidance and support navigating the multi-layered systems***

  Once the diagnosis is given, then parents embark on the journey of working with multiple interventional services from multiple providers. They have many questions about services, IEP's, medical versus educational services and how to access them all – and make it work with their schedule. I have guided many parents through this process.

- ***During times of crisis***

  Often parents experience a time when their child has a shift and they are in crisis: the child is not sleeping and keeping the whole family up at night, the child becomes aggressive, the school is telling parents that the current interventions are not working, or sensory issues increase. Parents have turned to the care coordinator to find out where to go next. Talking with them on the phone has often been sufficient to determine the need and preventing an office visit. The patient's need may be a new OT evaluation to determine sensory needs, an appointment sooner for medication management, or a referral to speech therapist to assist with supports in communication, among others.

Encounters between the care coordinator and the family were documented on the care coordination form. These were forwarded to Altarum and entered into a database. The database documented 179 care coordination encounters for 22 enrolled children. Of the 22 children enrolled in the pilot, 8 were classified as Level I, 8 as Level II, 2 as Level III, and 3 as Level IV. One child did not have a level filled in on the form. Of the 179 encounters, 167 listed the amount of time spent in the encounter. The average length of a care coordination encounter was about 22 minutes.

The care coordination record asked for the focus of each encounter. (More than one topic area could be listed for each encounter.) Table 16 shows the number of encounters that addressed each focus area and the number of enrollees in the pilot who addressed each area in at least one of their encounters. As the table shows, the focus areas most often mentioned were educational/school issues, which were addressed in 44.1 percent of encounters, and referral management, addressed in 38.5 percent. On the client level, nearly all clients needed help with referral management (95.5 percent), educational/school issues (86.4 percent), and clinical/medical services (81.8 percent) in at least one of their encounters.

Table 16.
Focus of Care Coordination Encounters, by Encounter and by Client

Encounters (n=179)			Clients (n=22)	
	N	%	N	%
Mental health	15	8.4	5	22.7
Developmental/behavioral	50	27.9	17	77.3
Educational/school	79	44.1	19	86.4
Legal/judicial	10	5.6	6	27.3
Growth/nutrition	11	6.1	8	36.4
Referral management	69	38.5	21	95.5
Clinical/medical	63	35.2	18	81.8
Social services	4	2.2	5	22.7

Care coordination needs listed on the encounter form included making appointments, following up on referrals, ordering prescriptions or supplies, reconciling discrepancies, coordination services, and attending IEP or team planning meetings. The vast majority of encounters (131 of 179, or 73.2 percent) listed coordination services as the need for the encounter. Fifty-three (29.6 percent) listed following up on referrals.

Care coordination activities are similarly limited in their range. Of the 179 total encounters, 105 (58.6 percent) were described as "phone with parent." Other activities listed on more than 10 encounter records include conferring with PCP (28), chart review (26), phone with agency (16), and email with agency (16).

The encounter form also recorded the negative outcomes prevented by the care coordination encounter and the positive outcomes that occurred. Many records did not list any outcomes prevented, but for those that did, the most common were disconnected intervention (34), delay in implementation of services (33), and receiving less than the recommended services (27). On the client level, 15 clients had at least one encounter that prevented a disconnected intervention, 14 had at least one that prevented a delay in implementation of services, and 12 had at least one that prevented the child from receiving less than the recommended services.

There was more variation in the outcomes that occurred. Table 17 shows the outcomes that resulted from the care coordination encounters on the encounter and the client level. The outcomes reported most commonly on both levels were that the family or child's needs were met, followed by advocacy for the family.

Overall, the encounter forms paint a picture of a care coordination service that is focused on meeting the needs of children and families and assuring their access to needed services.

Table 17.
Outcomes of Care Coordination Encounters, by Encounter and by Client

	Encounters (n=179)		Clients (n=22)	
	N	%	N	%
Referral to subspecialist	10	5.6	2	9.1
Referral to community agency	21	11.7	3	13.6
Referral to specialized therapies	10	5.6	5	22.7
Met family's needs	70	39.1	10	45.5
Met child's needs	77	43.0	10	45.5
IEP/IFSP established	3	1.7	2	9.1
Reconciled discrepancies between services recommended and those provided	14	7.8	5	22.7
Advocacy for family	55	30.7	10	45.5
Timelines decreased	25	14.0	7	31.8
Unmet needs	23	12.8	3	13.6
Access to medical model	23	12.8	3	13.6

Husson Pediatric reported that they successfully enrolled and enriched the lives of 32 patients and their families. They stated that the reason this pilot was of interest to them is that the current system of treatment for ASD is both confusing and unwieldy. Parents are not intuitively knowledgeable about what services are available, and what services are covered by the medical and educational models. Community case managers do serve as a guide through these difficult and confusing landscapes of treatment but that professional may not have the expertise in all the models and services available and have little to no knowledge about the medical needs of children with ASD.

Huson Pediatrics reported some general findings about the pilot:

- Parents most often sought out care management services upon initial diagnosis and during periods of crisis.
- **Challenges included**:
    - Playing phone tag with families
    - Obtaining consents
    - Making contact with outside agencies/service providers
    - Delaying access to treatment due to the bureaucracy associated with processing insurance applications and MaineCare.
    - Missing evaluations and/or a breakdown in communications between agencies.
    - Accessing appropriate community treatment. Although the law/rule is written with greater flexibility, many providers of services offered only non-inclusive, self-contained programs creating challenges to provide treatment in an inclusive environment so that appropriate peer modeling could occur.
    - Transitioning youth to adult healthcare. Other physicians/practices have communicated that they are not willing or prepared to receive older patients with ASD.
- **Successes for children who received pilot services included**
    - The ability to access insurance or enroll in MaineCare sooner allowing for quicker access to the medical model of care faster.
    - Improved timelines and organization resulting in more timely referrals for external community case management, occupational therapy, speech therapy, other evaluations, support groups, parent support contacts, appropriate educational programming, and other services.
    - Parents felt supported and validated

    - Access to solutions to behavioral issues could be discussed off hours via phone with a knowledgeable person. Troubleshooting took place and parents quickly learned what options and approaches were available to them. Referrals could quickly follow but families were often left with tools that they could immediately use to mitigate behavioral problems.

- **Practice wide changes as a result of the pilot included:**
    - All children were screened for an ASD at 18 months or 24 months using the M-CHAT screening tool. Should the patient "fail" the first part of the M-CHAT the physician administered the interview portion. This change allowed identification of children at risk of an ASD and a faster referral to Developmental Pediatricians for evaluation.
    - Establishment of a "support network" of parents with children with ASD who volunteer to talk about issues, concerns, feelings, and generally provide emotional support to other parents of children diagnosed with an ASD.
    - Development of a Husson Pediatrics Office Visit "social story" for the practice web site and Facebook page.
    - Increased provider awareness of available resources
    - Increased provider awareness of the importance of early identification and early intervention.

Perhaps one of the most exciting outcomes of the pilot was the practice wide adoption of using visual schedules. A visual schedule was prepared for routine screenings like blood pressure as well as an overall guide of what tasks would occur during the appointment. Husson reported that many children have been able to have calmer, effective appointments. One anecdote is of a child who, until now, was not able to tolerate a blood pressure screening for over nine years that is until now.

Four local news stations featured the story about the "One of a kind Autism program." The initial press release issued is below. It was sent by Eastern Maine Medical Center, the umbrella hospital organization of which Husson is a member.

> **EMMC Autism Program Bridges Gap Between Primary Care and Community Resources**
>
> Knowing where to go for help when your child needs specialty care can be confusing. When a child is diagnosed with Autism, the path to care can be a bewildering maze of educational and medical services. Parents are left to seek out and coordinate various treatments with little guidance.

The first place many families turn after an autism diagnosis is to their primary care office. “We’re naturally the ‘go to’ resource,” says Michael Ross, MD, pediatrician at EMMC Husson Pediatrics. “We saw an opportunity to increase our role in caring for these patients by helping parents access the various community resources available to them and their children. In the last four years, Dr. Ross; Rochelle Harriman, RN, autism care manager; and the staff at Husson Pediatrics have piloted an autism program that is like none other in Maine.

“There is no ‘one size fits all’ model for all children with autism,” indicates Rochelle. “Autism affects children on multiple levels, so parents are faced with seeking different types of services and therapies. Multiple agencies and service providers are involved and parents often feel overwhelmed navigating the systems. Finding ways to streamline therapies can make the difference in the overall progress a child makes.”

As the autism care manager, Rochelle guides parents toward agencies and programs that provide speech, social and occupational therapy, behavioral management, medications, and educational options tailored specifically for the child. With 19 years working with families of children with autism, Rochelle is adept at finding help. She knows each next step a parent needs to take, what services are covered by insurance, how to apply for MaineCare, which agencies provide which services, and how to find the correct forms to receive covered benefits.

“This liaison piece is huge,” says Danielle Goulette, a parent who took advantage of the autism program for her daughter, who was diagnosed with Autism at two years old, after late speech development. “I called Rochelle and she got back to me immediately,” continues Danielle, whose challenge was to figure out how to juggle a full time job and get her child all of the services she needed. “Rochelle helped me register the pre-school and scheduled her therapy appointments on site, which is incredible.”

Rochelle’s support of these families doesn’t stop at information about services and help connecting with agencies, parents also reach out for emotional support, as they may be new to understanding their own child’s needs. Families may experience stress as they learn to adapt to a child with autism, and some reach out once an issue erupts and they don’t know where else to turn.

‘‘We want our patients and families to know that we are here to help guide them through all aspects of care related to Autism spectrum: whether it be obtaining needed developmental therapy, physician consultations, or coordination with a subspecialist, all fall under the care provided by our office,’’ says Dr. Ross.

Husson Pediatrics begins developmental surveillance in infancy, and specifically screens children for autism at 16-18 months of age. “Research shows that early intervention and detection creates far better outcomes for the child and the family,” says Rochelle. During the screening, they look for symptoms of autism which includes lack of eye contact, problems developing social skills, communication and sensory issues, and sleep and intestinal issues. If an autism diagnosis seems to be a possibility, a referral is made to Mary Ellen Gellerstedt, MD, EMMC Developmental Pediatrics, or Joanna Dotts, DO, EMMC Developmental Pediatrics to determine if Autism is present. After a diagnosis is made, parents connect with Rochelle and together they begin to plan the best course of treatment for their child.

“The autism program at EMMC’s Husson Pediatrics is truly groundbreaking. They have transformed care for children with autism,” says Nancy Cronin, executive director, Maine Developmental Disabilities Council, an organization that funds the program. “This is about higher quality of care of kids,” says Nancy, “EMMC’s Husson Pediatrics is cutting edge. It is a true center of excellence.”

Goal 5: Improve surveillance and service system data related to the identification and care of children and youth with ASDs for use by policy-makers

☑ *Objective 5.1 By August 31, 2013, Maine will have developed a comprehensive data system to track screening, diagnosis and referral results reported by medical practitioners, HeadStart, WIC, public health nurses, and home visitors.*

Facilitating Autism Screening and Treatment (FAST)

A module has been developed within an existing data system called ChildLink. ChildLink manages Newborn Hearing and Screening as well as the state bloodspot data so it is a data system providers are already familiar with. Within Childlink a module has been developed to record screenings of the Modified Checklist for Autism and Toddlers (M-CHAT), communicate screening results to primary care physicians (PCP), record necessary follow up screens and facilitate referrals to evaluators when appropriate. Further, the module has been designed for evaluators to record the ultimate diagnosis of a child creating a registry and communicating with early intervention providers.

At the present, there are still many unknown factors with regard to working with PCP's, such as the feasibility of interfacing with the electronic management systems at each PCP's office and using the State's immunization data system as a portal or Health Information Technology for PCP's to access autism screening data. So, although the module has been created, it is not fully interfaced with partnering systems. This work will likely continue well past the grant term as the State of Maine works to integrate all electronic medical records with State public health systems.

☑ *Objective 5.2 By August 31, 2013, data from ChildLink, educa5tional systems, MaineCare, and other sources will be utilized to better evaluate prevalence of ASDs, types of services utilized and timeframes for accessing those services, as well as current and potential unent needs.*

In 1984, there were fewer than 40 individuals identified as having autism in Maine. To provide services to them, the 111th Legislature passed the Autism Act of 1984. At the turn of the 21st century, our schools were serving 594 students under the category of autism. In 2009, schools reported 2,471 students being served in that category. The December 1, 2012 Child Count data collected by schools reported 2,989 students being served, that is a 21% increase within the last decade. In 2012, MaineCare paid claims for more than 5,381 Maine citizens diagnosed with an ASD, that is a 29% increase from just three years ago. Maine is not alone with this increase. In 2012, the U.S. Centers for Disease Control (CDC) updated its estimated prevalence numbers to 1:88[2]. In fact, the growing epidemic is worldwide.

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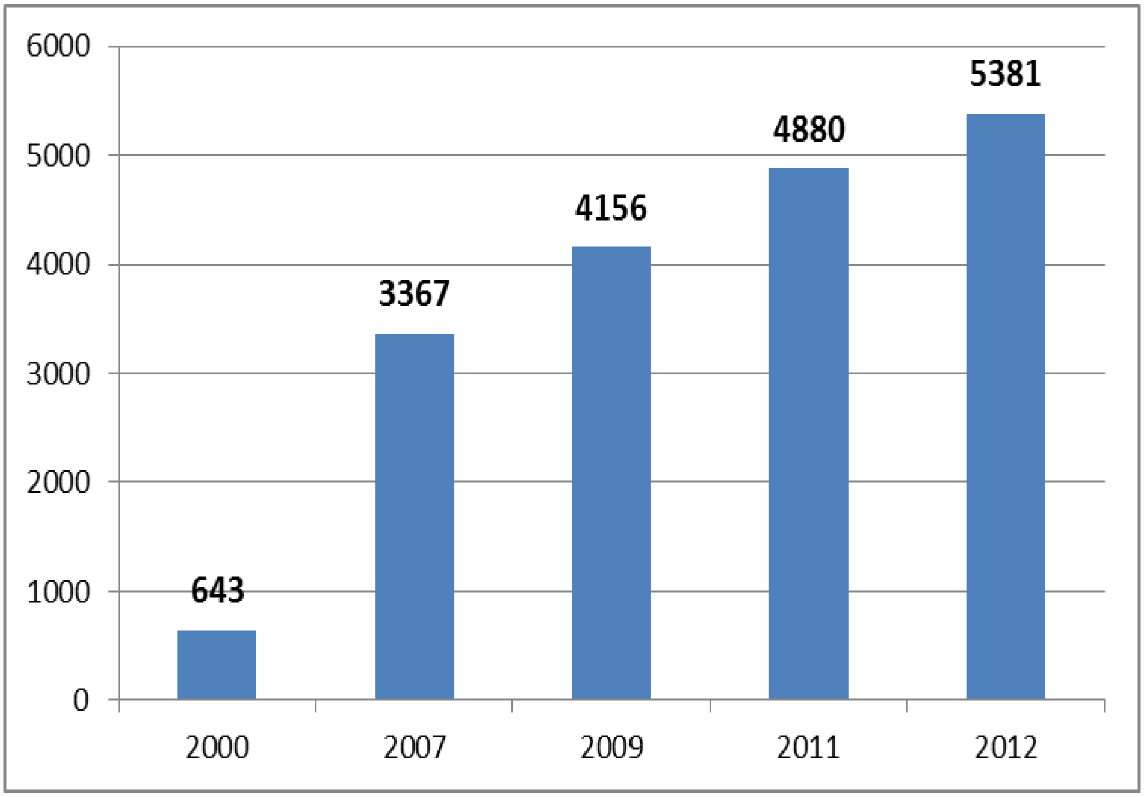
[2] http://www.cdc.gov/ncbddd/autism/data.html Accessed 3/29/2013

Studies in Asia, Europe and North America have identified individuals with an ASD with an average prevalence of about 1%. A recent study in South Korea reported a prevalence of 2.6%.[3]

In 2007, MaineCare paid claims for 3,367 members with an ASD. In 2012, that number jumped to 5,381. **That is an increase of 60% just within the last five years. The increase is over 730% since the turn of the twenty-first century.**[4]



Department of Education (DOE) data also indicates a dramatic increase in the number of students being served for special education under the category of autism. There has been a 34% increase within just the last five years and over a 430% increase since the turn of the twenty-first century.[5]

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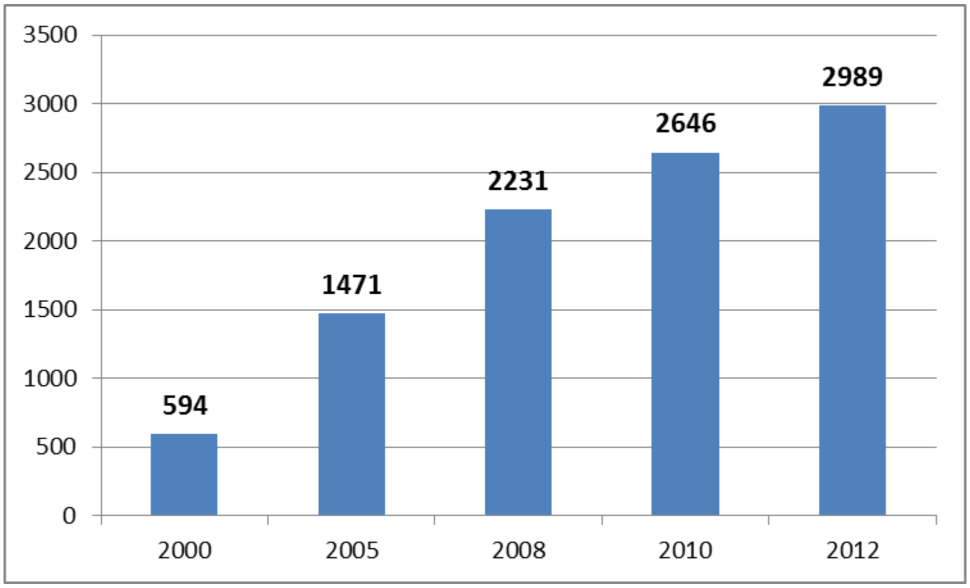
[3] Kim YS et al (2011) Prevalence of autism spectrum disorders in a total population sample. American Journal of Psychiatry 2011 Sep;168(9):904-12

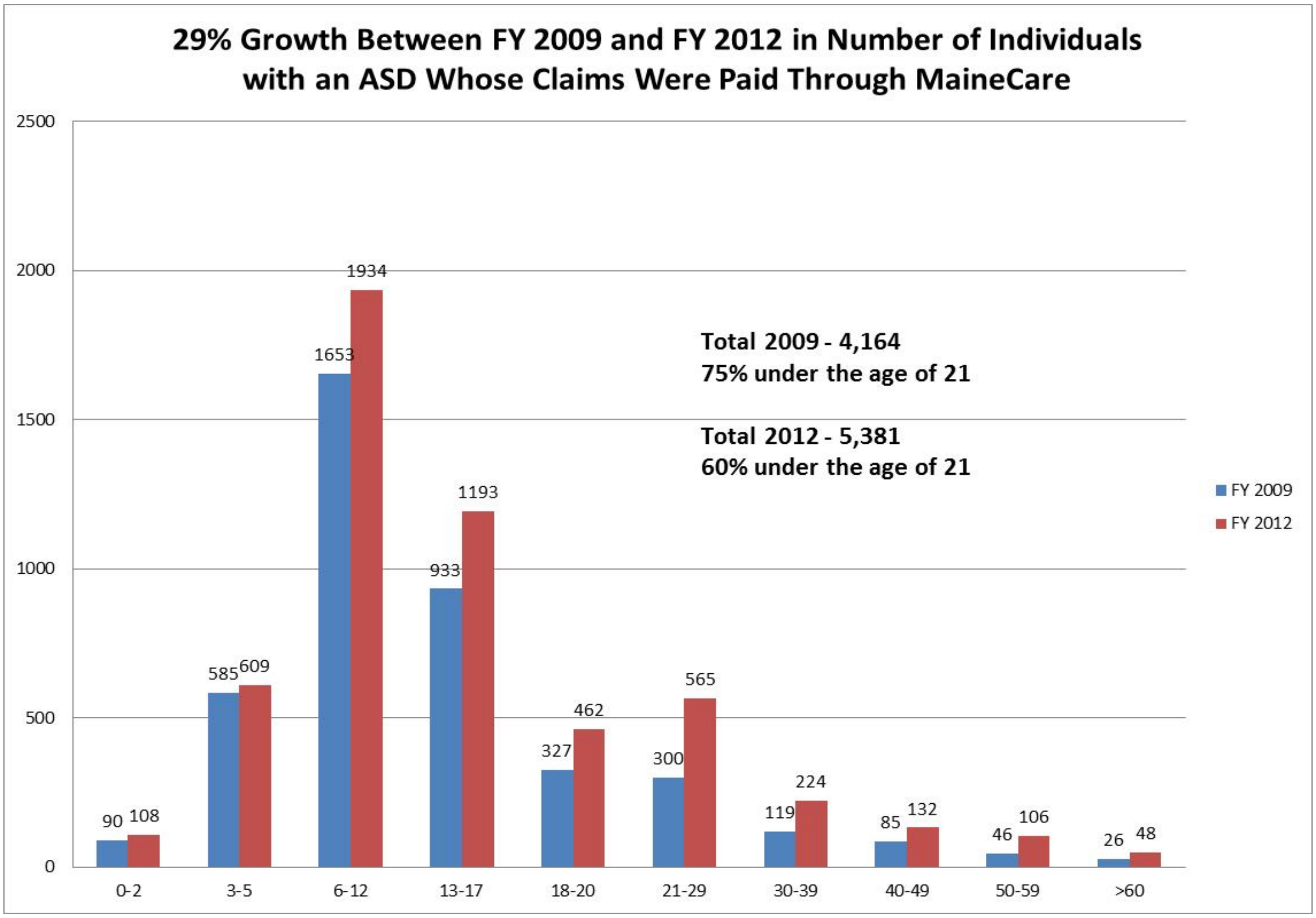
[4] MaineCare is an income-dependent service.

[5] DOE Childfind data 2000-2012



According to MaineCare claims data, there has been an increase in the number of individuals with an ASD in every age group**. In the 2011 Autism Report, youth ages 18-20 was the fastest growing group of over 100 individuals with an ASD. Today, young adults aged 21-26 are the fastest growing group of over 100,** indicating that the growing population of individuals with ASD is reaching adulthood. **The largest number of individuals with ASD continues to be the age group of those six through 12 years of age.**

Age	2007	2009	2012	3 yr % Increase	5 yr % Increase
0-2	91	90	108	20%	19%
3-5	470	585	609	4%	30%
6-12	1,304	1,653	1,934	17%	48%
13-17	774	933	1,193	28%	54%
18-20	239	327	462	41%	93%
21-26	184	240	429	79%	133%
27-64	296	324	620	91%	109%
65+	9	12	26	117%	189%
Total	**3,367**	**4,164**	**5,381**	**29%**	**60%**



The 124th Legislature passed Chapter 635 (LD-1198), which mandates that insurance companies provide coverage for the diagnosis and treatment of ASD for all children under the age of six. The law went into effect in January of 2011. There are no limits placed on the number of visits or cost that must be covered, except that service policies may limit coverage provided for applied behavior analysis therapies to $36,000 per year. The 126th Legislature is currently considering a bill (LD-347) that would broaden the current law and provide coverage for the diagnosis and treatment of ASD for all children and youth under the age of twenty-one. That bill has been carried over and will be reviewed by the insurance committee spring of 2014