Autism Diagnosis Education Project

A Look at the First Two Years of Expansion

Year 1: October 2012 – June 2013
Year 2: July 2013 – June 2014
Introduction

The Autism Diagnosis Education Project (ADEP) facilitates unique partnerships between community-based primary care practices and professionals providing early intervention and early childhood services to increase access to local and timely standardized, comprehensive diagnostic evaluations for children suspected of having an autism spectrum disorder. Launched in 2008, the Autism Diagnosis Education Pilot Project (ADEPP) was originally piloted through funds from the Ohio Department of Health (ODH) and administered by the Ohio Chapter of the American Academy of Pediatrics. The pilot concluded in June 2011. The project’s efforts continued again beginning in October 2012 with funding from the Governor’s Office of Health Transformation awarded to the Ohio Department of Developmental Disabilities (DODD) for the expansion of ADEP. The Department has partnered with Akron Children’s Hospital, Family Child Learning Center, and the Ohio Center for Autism and Low Incidence (OCALI) to coordinate and implement the ADEP expansion. The project’s work aligns with the Ohio Autism Recommendations\(^1\), which emphasizes the importance of early identification and diagnosis of autism.

Outlined below is a summary report, reflecting on the accomplishments and goals of the expansion since October 2012, including target goals and analysis of the current status of the project. Using the data collected, along with feedback from participating teams, recommendations are provided as well on how to move forward.

Framework

A grant agreement between DODD and OCALI has been created for ADEP expansion work. The agreement delineates roles and responsibilities of the Department and OCALI (the Grantee). The agreement language outlined below is the framework of the project:

\(\text{The Department (DODD) desires to obtain specific services to implement ADEP, a project that will provide multi-level training to stakeholders to achieve the following:}\)

\begin{itemize}
  \item increased knowledge of the Autism Diagnosis Education Project (ADEP) initiative;
  \item increased awareness of the necessity for early diagnosis and intervention;
  \item ensure that families with a member of autism have access to high quality early identification, diagnosis and programming; and
\end{itemize}

\(\text{Grantee would provide a focus on the autism diagnosis of young children with autism for the diagnostic teams and physicians. This project will:}\)

\begin{itemize}
  \item identify high-quality diagnostic training procedures;
  \item develop a plan to ensure that young children from traditionally under-represented groups have access to early diagnosis;
  \item train teams including physicians on these procedures;
  \item link diagnostic entities and provide a hub for resources in early diagnosis.
\end{itemize}

\(1\) See Appendix for link to complete document of the Ohio Autism Recommendations
The deliverables to be achieved through this agreement are as follows:

- **Deliverable 1** – Recruit as close to 10 (ten) committed teams as possible per year and provide a comprehensive training experience in the diagnostic process for physicians and early intervention professionals. Engage trained teams in follow-up technical assistance and coaching for sustainability, using team data as assessed by biostatistician to make recommendations on project adjustments, as well as using data to develop annual summary report.

- **Deliverable 2** – Complete an annual summary report of data collected through the Diagnostic Partnership teams to document ADEP project impact.

- **Deliverable 3** – Maintain website presence to market project successes and disseminate ADEP information.

### Expansion of Teams

The growth of ADEP has occurred in 4 separate waves: two waves under the Autism Diagnosis Education Pilot Project (ADEPP, 2008-2011), and two waves under the expansion (ADEP, 2012-2014). A pilot of 5 counties was launched in 2008, with an additional 26 counties joining in 2010. When the project expanded in 2013, 20 more counties joined the effort.

![Map showing expansion of ADEP](image)

- **47** Participating Counties
- **317** Participating Service Providers
- **43** Partner Physicians
- **29.9** months

Average age of diagnosis in ADEP versus approximately 4 years old for national average²

Summary and Highlights of Data and Deliverables

As project leadership was assembled in the latter months of 2012 and early 2013, a survey was conducted via phone of all teams who had established ADEPP teams through 2008-2011 for the purpose of collecting information on their status and the number of children they had evaluated since the conclusion of the pilot in June 2011. From this survey, project leadership discovered that a majority of teams had continued to function in the interim, evaluating approximately 150 children suspected to have ASD. Following this survey process, a formal recruitment of 13 counties in April 2013 and 7 counties in September 2013 was completed, bringing the total number of participating counties with diagnostic partnerships to 47. As an expectation of their involvement, teams were asked to submit data on an ongoing basis, in order to track whether target goals were being met.

Data Collection

Diagnostic teams submitted all data via a brief online survey, which asked for the following information on the children seen by the diagnostic team:

- County
- Child's ID
- Child's date of birth
- Child's gender
- ADOS-2 module used to evaluate child
- Primary diagnosis given by partner physician
- Child's age at which family was first concerned
- Child's age at first contact with Help Me Grow (HMG) or local education agency (LEA)
- Child's age at ADEP diagnosis
- If child is given an ASD diagnosis, what intervention did he/she receive

The data from this material indicated a series of key results, reflecting information gathered between January 1, 2013 and April 30, 2014. As this information was collected, project leadership routinely provided a data summary back to the teams through monthly webinars as a means of indicating ADEP’s progress in achieving targets. A biostatistician was hired to evaluate and analyze the data submitted. The biostatistician was then able to take the provided data and offer a concise snapshot of the project’s goals, including the percentage of children diagnosed, average ages, lag time and age of diagnosis.
Target Goals
Three target goals were outlined for the ADEP expansion:

1. Decrease the lag time from initial family concern to diagnosis to less than 9 months.
2. Decrease the lag time from initial contact with Help Me Grow (HMG) or Local Education Agency (LEA) to diagnosis to within 90 days.
3. Reduce the age at which a child is diagnosed to 30 months.

Expansion Targets
As teams continue to be reliable and efficient, ADEP moves closer and closer to its target goals, as evidenced by the graphic shown here. The median, rather than the mean, is most indicative of how close the project is to reaching its goals. One diagnostic team in particular is an outlier because they often see children over three years of age, skewing the data somewhat. The median brings the target into sharper focus and accounts for this exception. For both the time from initial family concern to diagnosis and for the time from initial contact with HMG or LEA to diagnosis, the results are just shy of the target goals. The age of diagnosis has been reduced to 29.9 months, achieving the goal of less than or equal to 30 months. Considering the national average is approximately 4 years old for the average age of diagnosis, this is a significant result.

<table>
<thead>
<tr>
<th></th>
<th>ADEP Target</th>
<th>Findings from 1/1/2013 through 4/30/14</th>
</tr>
</thead>
</table>
| Time from initial family concern to diagnosis | < 9 months | Mean = 11.81 mos  
Median = 10.00 mos |
| Time from initial contact with HMG or LEA to diagnosis | < 3 months  
(< 90 days) | Mean = 8.43 mos  
Median = 5.00 mos |
| Age at diagnosis | ≤ 30 months | 29.9 mos |
| Time from initial concern to contact with HMG/LEA |  | Mean = 4.6 mos |
Percentage Diagnosed

Of the 151 children evaluated by diagnostic teams, data reflected that 57% of the children received a diagnosis of ASD. Other primary diagnoses were language delays/disorders and developmental delays. The category of “Other” typically reflected children whose family opted not to see the partner physician in order to complete the evaluation or the child was sent on further to a regional diagnostic center to determine a diagnosis.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Response Percentage</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Spectrum Disorder</td>
<td>57%</td>
<td>86</td>
</tr>
<tr>
<td>Language Delay/Disorder</td>
<td>16%</td>
<td>24</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>5%</td>
<td>8</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>2%</td>
<td>3</td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>0%</td>
<td>0</td>
</tr>
<tr>
<td>ADHD</td>
<td>1%</td>
<td>1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0%</td>
<td>0</td>
</tr>
<tr>
<td>Depression</td>
<td>0%</td>
<td>0</td>
</tr>
<tr>
<td>Behavior Disorder</td>
<td>2%</td>
<td>3</td>
</tr>
<tr>
<td>Reactive Attachment Disorder</td>
<td>1%</td>
<td>1</td>
</tr>
<tr>
<td>Genetic Disorder (e.g., Fragile X)</td>
<td>0%</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
<td>25</td>
</tr>
</tbody>
</table>
Training and Technical Assistance

ADEP teams confirm that ongoing training and technical support is vital to the sustainability of the local diagnostic teams, particularly monthly webinars and regular ADOS-2 training. Over the course of the last 18 months, 13 webinars, 4 of which were ADOS-2 reliability webinars and 9 which focused on overall project updates, current research and partner physician resources were conducted. Six days of ADOS-2 training over the span of 10 months were provided, with approximately 185 attendees total.

Both the webinars and the ADOS-2 trainings serve several integral purposes:

- Providing current research and information to the field that is highly targeted to their needs, preventing them from having to filter through mounds of research on their own time.
- Connecting everyone across the state in order to disseminate consistent and cohesive information to all who participate.
- Allowing a platform by which people can score and evaluate the ADOS-2 and compare their scores to our ADOS-2 training facilitator; this allows people to maintain their skill level on the tool, even if they are not regularly using it in day-to-day practice.
- Providing a means to train any new staff members who have joined the partnership between trainings.

ADEX Regional Meetings

Over the course of April and May, 2014, ADEP staff leadership held 4 regional meetings across the state and spent face-to-face time with at least 21 diagnostic partnerships in order to address concerns, but also to allow teams to network. The teams were also asked to provide feedback on overall management of the ADEP project moving forward. Several key themes began to emerge from the regional meetings:

- ADOS-2 training is a high priority, both for new staff and reliability for existing staff.
- Monthly project webinars are invaluable.
- Awareness of ADEP is lacking at the local level, both by families and community physicians.
- Teams appreciate when template marketing material is created for them.
- Team members believe the project is worthwhile and are 100% committed, even despite barriers.

Barriers to Growth

As ADEP has progressed, there are consistent barriers that continue to arise across the system, both at the local level and across the larger system as a whole. The most common barriers expressed are as follows:

- Recruitment/maintenance of partner physicians
- Lack of community awareness of ADEP and services provided
- Lack of interest, understanding, awareness, or resources from non-participating counties
  - Some counties are simply too small to sustain a team, potentially only seeing 1 or 2 children per year.
  - Counties often have no sense of urgency or understanding regarding the importance of diagnosing ASD and intervening early.
- Staff turnover
- Local politics
Recommendations for Moving Forward With Expansion

In order to continue to provide sufficient support to participating teams as well as to attract and train counties not yet participating, the following recommendations are suggested for the 2014-2015 fiscal year:

- Provide additional ADOS-2 training for those teams who have had staff turnover.
- Provide ongoing ADOS-2 support for all in order to maintain reliability.
- Assist counties who are currently without a medical partner by helping them formulate a strategy for recruitment and retention.
- Mentor the counties who have the appropriate structures in place but have not yet seen a child.
- Informally survey the remaining non-participating counties to determine if they either:
  A) Have a local referral and evaluation process already in place;
     - if so, invite them to informally join ADEP and allow them to participate in monthly webinars.
  B) If they do not have existing mechanisms already in place for families to receive local access to an autism diagnosis, then invite them to formally join ADEP, providing the necessary training and support.
Appendix
Timeline of training and support provided from January 1, 2013 – June 30, 2014, including attendance numbers

2013

March
ADOS-2 refresher training, 69 attendees

April
New team training, 60 attendees
1 physician-only webinar (no attendance recorded)

May
ADOS-2 training, Part 1, 70 attendees

June
1 webinar (no attendance recorded)

July
2 sessions of ADOS-2 training
  - Part 1, 20 attendees on July 8
  - Part 2, 79 attendees on July 9

August
1 webinar (no attendance recorded)

September
Recruitment of 7 new teams, 9 new physicians
1 webinar, 51 attendees

October
Visits to three teams (Belmont, Erie, and Lorain Counties)
New team training, 46 attendees
ADOS-2 training, Part 1, 46 attendees
1 webinar, 47 attendees

November
1 webinar, ADOS-2 reliability, 52 attendees
Conference call with new partner physicians

December
1 webinar, 41 attendees
ADOS-2 training, Part 2, 49 attendees

2014

January
1 webinar, ADOS-2 reliability, 36 attendees

February
1 webinar, 37 attendees

March
1 webinar, ADOS-2 reliability, 36 attendees

April
1 webinar, 47 attendees
Regional meeting, Delaware County, 10 attendees, 7 counties represented

May
Regional meeting, Clermont County, 7 attendees, 5 counties represented
1 webinar, ADOS-2 reliability, 18 attendees
Regional meeting, Wood County, 11 attendees, 7 counties represented
Regional meeting, Portage County, 12 attendees, 2 counties represented

June
1 webinar, 42 attendees

Additional Resources
Ohio Autism Recommendations
www.ocali.org/project/ohio_autism_recommendations

ADEP website
www.ocali.org/adep

Youtube: Spotlight on Early Diagnosis and Early Intervention in Ohio
http://youtu.be/WJ1HN_ELrkg

Questions?
Contact Courtney Yantes,
Early Childhood Grants Coordinator, OCALI
courtney_yantes@ocali.org or 614.410.0701