

Supplemental Online Content

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eAppendix

This supplemental material has been provided by the authors to give readers additional information about their work.

eAppendix. Protocol details for *The effectiveness of screening in Early Intervention settings to improve diagnosis of autism and reduce health disparities: a difference-in-differences analysis*

This document provides additional details regarding:

- I. Protocol details
 - a. Training to research reliability
 - b. Comparison condition: Standard care in Early Intervention
- II. Data analysis
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 - b. Data access
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 - e. Variable coding
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I. Protocol details

I.a. Training to research reliability

The Autism Diagnostic Observational Schedule (ADOS) has very specific requirements for training. There are two distinct levels of training: 1) national research reliability certification and 2) internal within laboratory research reliability certification. Some of our doctoral students had obtained national research reliability certification, which requires attending both clinical and research didactic training sessions, coding existing videotaped ADOS administrations at 80% agreement with expert coders, as well as submitting videotapes of one's own administrations and demonstrating appropriate administration techniques as well as achieving 80% agreement overall and for the diagnostic algorithm items with a nationally certified trainer. Some of our graduate students and research assistants achieved internal within lab reliability. This requires training that is conducted by a nationally research reliable certified individual in the lab, achieving 80% reliability on coding total items and the diagnostic algorithm for existing ADOS consensus tapes and three consecutive personal administrations of the ADOS. Doctoral students and research assistants demonstrated reliability on Modules 1 and 2, 3 and 4, and the toddler module. Although not required by national standards for ADOS administration, given the high number of toddler module ADOS administrations we anticipated due to the very young age of our sample, we added a requirement of achieving 80% agreement for total items and the diagnostic algorithm for three consecutive Toddler Module administrations.

I.b. Comparison condition details – standard care in Early Intervention (EI)

The Program for Infants and Toddlers with Disabilities (Part C of IDEA), a federally mandated program, was established by Congress in 1986 to augment the development of infants and toddlers with disabilities and improve families' capabilities for meeting their children's needs. Although a federal grant program sets standards for states for organizing statewide early intervention services for children under three years of age, there is great variability in state-level implementation across the USA. Relative to the national average of engaging 2.8% of families in EI, Massachusetts had the highest reach of all states in 2019, engaging 9.4% of families in EI, reflecting both a relatively high rate of developmental screening and the use of broad eligibility criteria (<https://stateofbabies.org/data/#/Massachusetts>). Broadly, the Massachusetts EI program is designed to support families with children under the age of three years who have developmental delays or are at risk for developmental delays (<https://www.mass.gov/info-details/about-massachusetts-early-intervention-ei>).

EI services are meant to help support families and caregivers and to enhance the development and learning of infants and toddlers through individualized, developmentally appropriate activities within the child's and family's everyday life. Providers can have a range of backgrounds and training (e.g., speech and language pathologists, occupational therapists, social workers, developmental specialists) and are expected to work in a transdisciplinary manner, tailoring services to meet the developmental needs of the child. In addition to helping children gain knowledge, skills and promote children's developing independence, EI supports families in knowing their rights, communicating their understanding of their child's needs and capacities, and offering strategies to help parents facilitate their

children’s development. Families are given an Individualized Family Services Plan (IFSP) that specifies child and family goals and the duration and number of sessions that children will receive.

For all of the programs included in the current report, EI services are designed to be collaborative and individualized to the child’s developmental needs and the family’s priorities and cultural values. Core tenets of EI include: 1) the importance of caregiving relationships in promoting children’s learning and development; 2) that infants learn best through repeated opportunities to practice new skills; and 3) caregivers have the most important role to play in their children’s development. Therefore, providers work with parents and other caregivers as well as with early educators who may be involved in the child’s day-to-day care in the child’s natural environments. Service delivery hours may range from 30 minutes per month to several hours per week. EI specialists may learn about the child and family’s routine daily activities, develop strategies to support children and families to achieve IFSP outcomes, help caregivers practice new skills or introduce new activities, and help ensure that children and families are efficacious in learning new skills. Importantly, there are no out-of-pocket costs to families who receive EI services.

What distinguished the intervention sites from their comparison sites was that the intervention sites were trained and supported in delivering a two-stage screening process, which included two paper-and-pencil screeners completed by families at stage 1 and an observational screener completed at stage 2. Providers were also able to expedite referrals by booking families who failed the stage 2 screening for a university-based diagnostic evaluation for autism spectrum disorder (ASD). To the extent that children received diagnoses of ASD through the multi-stage screening process, children and families would be eligible for additional ASD-tailored services, available through the MA EI Part C system, based on receipt of an ASD diagnosis.

EI in Massachusetts is not permitted to provide diagnostic evaluations to make determinations about ASD and they can’t formally refer children for ASD diagnostic evaluations. When EI providers suspect that a child has an ASD, they may encourage caregivers to talk with the child’s pediatrician to obtain a referral for a diagnostic evaluation. However, many EI specialists report having challenges in coordination with clinicians, including negative experiences and encountering delays in diagnosis. Such challenges present barriers to EI providers leveraging their unique position to observe children’s behavior in naturalistic settings over longer periods of time. Moreover, when children in Massachusetts are able to obtain a diagnosis of ASD, (often after many months on a wait-list) children and families become eligible for ASD-tailored high intensity services that are offered in addition to the general EI services that they have been receiving. The most common intervention offered in Massachusetts is ABA, but some providers offer naturalistic developmental behavioral interventions. These high-intensity services are also provided in naturalistic settings (i.e., home, childcare), do not incur out-of-pocket costs, and range from 3- to 15 hours per week. These high-intensity ASD-tailored services are not available unless a child has a formal diagnosis of ASD.

II. Data analysis

II.A. Hypothesis

Analyses in this paper pertain to hypothesis #1 as specified in the IRB protocol submitted to the Massachusetts Department of Health, namely: “Children with ASD enrolled in EI programs implementing our two-stage screening process will be more likely to be identified...regardless of race/ethnicity, language, or poverty status” (p 1)

II.A. Data access

Instructions to apply for access to Massachusetts Department of Health confidential records data can be found at: <https://www.mass.gov/how-to/apply-for-access-to-mdph-confidential-records-data>

II.B. Dataset structure

- Dataset was structured by person-quarters
- Implementation was staggered at the convenience of the three participating sites (not randomly assigned)
- The screening protocol was implemented at each of the three sites as described in the figure below

II.C. Sample sizes per quarter

Sample sizes per quarter are reported in eTable 1, below.

eTable 1. Flow diagram of sample sizes available per quarter over 6 years								
Project Year	Project Quarter	Dates		Sample sizes available				
				Implementation Sites			9 comparison sites	
				1	2	3		
1	1	Jul-12	-	Sep-12	550	444	342	3630
	2	Oct-12	-	Dec-12	562	442	347	3725
	3	Jan-13	-	Mar-13	604	458	381	3947
	4	Apr-13	-	Jun-13	653	476	385	4193
2	5	Jul-13	-	Sep-13	680	483	364	4468
	6	Oct-13	-	Dec-13	666	506	382	4600
	7	Jan-14	-	Mar-14	665	497	389	4736
	8	Apr-14	-	Jun-14	652	461	369	4580
3	9	Jul-14	-	Sep-14	739	490	411	5074
	10	Oct-14	-	Dec-14	745	472	422	5084
	11	Jan-15	-	Mar-15	737	491	412	5139
	12	Apr-15	-	Jun-15	727	480	420	5242
4	13	Jul-15	-	Sep-15	739	477	391	5289
	14	Oct-15	-	Dec-15	717	460	392	5316
	15	Jan-16	-	Mar-16	691	480	374	5413
	16	Apr-16	-	Jun-16	677	514	374	5563
5	17	Jul-16	-	Sep-16	695	511	334	5657
	18	Oct-16	-	Dec-16	683	500	332	5524
	19	Jan-17	-	Mar-17	688	496	331	5555
	20	Apr-17	-	Jun-17	692	483	334	5659
6	21	Jul-17	-	Sep-17	722	510	331	5609
	22	Oct-17	-	Dec-17	673	507	336	5544
	23	Jan-18	-	Mar-18	694	484	330	5498
	24	Apr-18	-	Jun-18	755	464	344	5460

II.D. Variable coding

Enrollment

- Each participant was coded as enrolled if a service occurred in that quarter

ASD diagnosis (primary outcome)

- If child was listed in the “EHS AUTISM SPECIALITY” datafile, quarter of 1st diagnosis was coded = 1 if “date of confirmed Autism Spectrum Disorder” diagnosis occurred during that quarter. Among ASD cases identified, 99.2% had a date of diagnosis recorded in the “EHS AUTISM SPECIALITY” datafile
- If child was not listed in “EHS AUTISM SPECIALITY” but service = “S Autism Service” or “J Autism Intake”, quarter of 1st diagnosis was coded = 1 if date of service occurred during that quarter

The primary outcome was coded as a binary variable with value = 0 in each quarter during which a child met eligibility criteria but had not yet received an ASD diagnosis, value = 1 during the quarter in which a child received an ASD diagnosis, and value = missing for any quarter thereafter.

Insurance status (public vs private)

- Coded based on “Insurance” in the “INSURANCE INFO” datafile
- Coded based on specific insurance plans using the following code

```
gen d_insure = . , after(cli_d_primlang)
    label define insure 1 "1 Public" ///
    0 "0 Private", modify
    label values d_insure insure
```

```
replace d_insure = 1 if primaryins == 00 |///
primaryins == 02 |///
primaryins == 06 |///
primaryins == 08 |///
primaryins == 34 |///
primaryins == 35 |///
primaryins == 38 |///
primaryins == 43 |///
primaryins == 44 |///
primaryins == 47 |///
primaryins == 48 |///
primaryins == 49 |///
primaryins == 50 |///
primaryins == 51 |///
primaryins == 67
```

```
replace d_insure = 0 if primaryins == 01 |///
primaryins == 18 |///
primaryins == 20 |///
primaryins == 21 |///
primaryins == 22 |///
primaryins == 24 |///
primaryins == 25 |///
primaryins == 26 |///
primaryins == 27 |///
primaryins == 28 |///
primaryins == 36 |///
primaryins == 40 |///
primaryins == 41 |///
primaryins == 60 |///
primaryins == 61 |///
primaryins == 63 |///
primaryins == 65 |///
primaryins == 66 |///
primaryins == 88
```

Child race/ethnicity

- Race and ethnicity were coded as separate variables using NIH definitions
- In DPH files, “Hispanic” ethnicity is listed under “Child’s race” and is also a separate variable (“Child’s cultural info/ethnicity”) in the “DEMOGRAPHICS” datafile. We coded Latinx=1 if Hispanic was listed under “race” or was recorded in the separate variable.

- We coded race directly from “Child’s race”. If only “Hispanic” was selected, race was recorded as missing. As indicated below, race was rarely coded as missing for this reason.

Child sex

- Child sex was recorded in multiple DPH variables. In the vast majority of cases, recorded values were invariant as expected. When variation occurred, we assigned the value that occurred in $\geq 75\%$ of cases. In the rare instances in which this threshold was not met, the value was recorded as missing and handled through multiple imputation.

Household income

- Directly coded from “Annual Family Income” in the “FAMILY INFORMATION” datafile

Preferred language

- Directly coded from “Language” in the “CLIENT INFORMATION” datafile

EI Sites

- The following program ids were included: 01, 02, 05, 16, 17, 20, 21, 27, 37, 44, 47, 49

II.E. Multiple imputation

Descriptive analyses revealed limited missing data with no clear pattern.

eTable 2. Covariates with missing values

Race/ethnicity	0.2%
Insurance status	2.81%
Language (English, Spanish or other)	0.02%
Poverty Status	2.76%

Multiple imputation accounted for site and included a logit link for individual categories of race/ethnicity, public vs private insurance statuses, and language categories (English, Spanish, or other), whereas an ordinal logit link was included for poverty status. Child sex was included as an auxiliary variable.

II.F. Use of propensity scores

Propensity scores are calculated at the individual level to balance on baseline differences at the group level. A common example would be to test for the effects of a medication while controlling for differences between individuals who did and did not receive that medication. Such differences may include variables related to the need for such medication (e.g., disease severity) as well as access to treatment (e.g., insurance status). We recognize that individuals became eligible for the screening intervention depending on the EI site at which they received care. Nevertheless, propensity scores at the individual level can be effective in controlling for confounding attributable to site-level differences in demographic variables. In our analyses, propensity scores were included in all regression models as inverse probability weights.