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*South Carolina Children's
Educational Surveillance Study*

The South Carolina Children's Educational Surveillance Study: SUCCESS

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SUCCESS Research Team

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Acknowledgements

- Autism Speaks
 - Michael Rosanoff
- CDC
 - Cathy Rice, Marshalyn Yeargin-Allsopp
- Young Shin Kim (consultant)
- Our *many* community partners



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Prevalence

- ASD Prevalence = number of people with ASD in a population/total population
 - How is ASD defined?
 - How is ASD measured?
 - Who is represented and who is missed?
- Understanding ASD prevalence is critical
 - Are we equipped to provide help to everyone who needs it?





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Methods for evaluating prevalence

- Surveys*
- Registries*
- Administrative counts of people receiving services for ASDs*
- CDC ADDM Network (active case finding approach)
- Population based screening and assessment

*Require prior diagnosis



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CDC

Autism Speaks

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Community

MUSC



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IACC Question 7: What other infrastructure and surveillance needs must be met?

Calculate the Prevalence of ASD

Compare DSM-IV to DSM 5

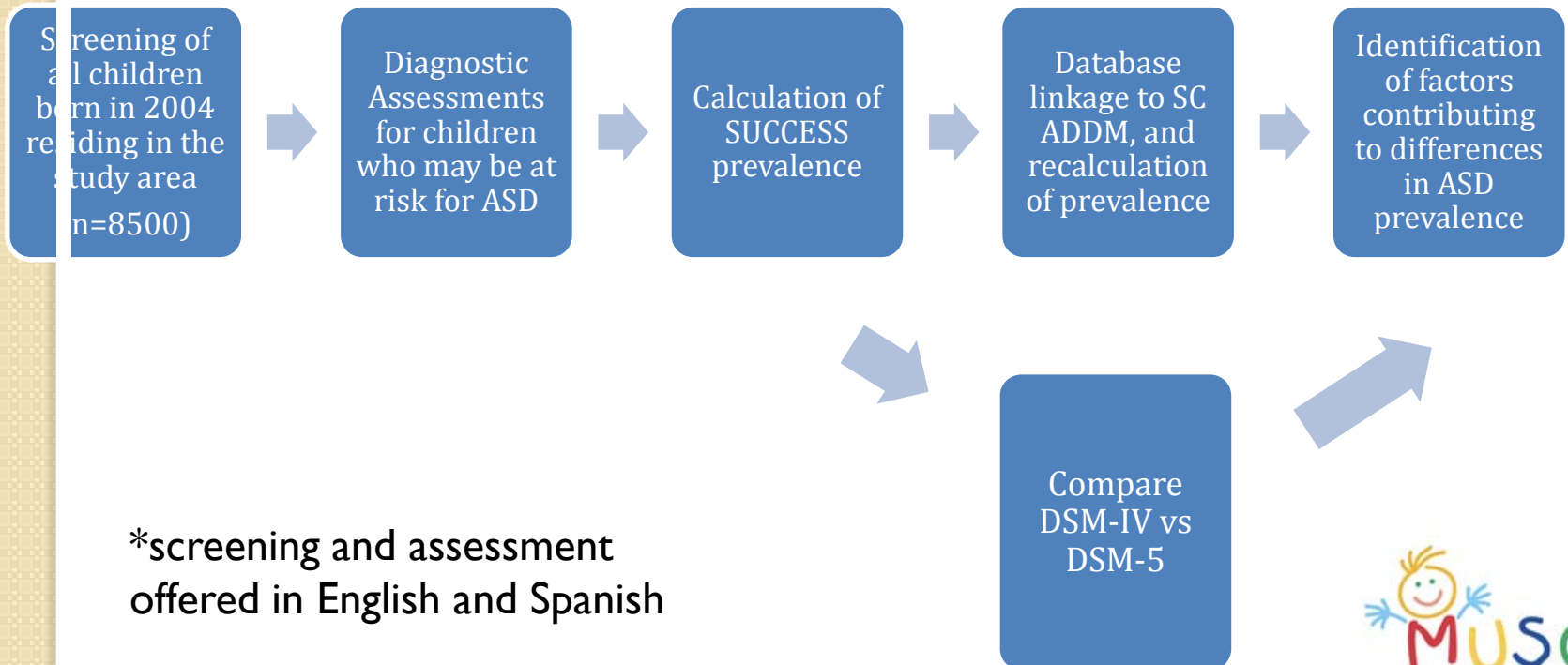
Compare to findings using CDC methodology



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SUCCESS: A population-based screening and assessment study



*screening and assessment offered in English and Spanish

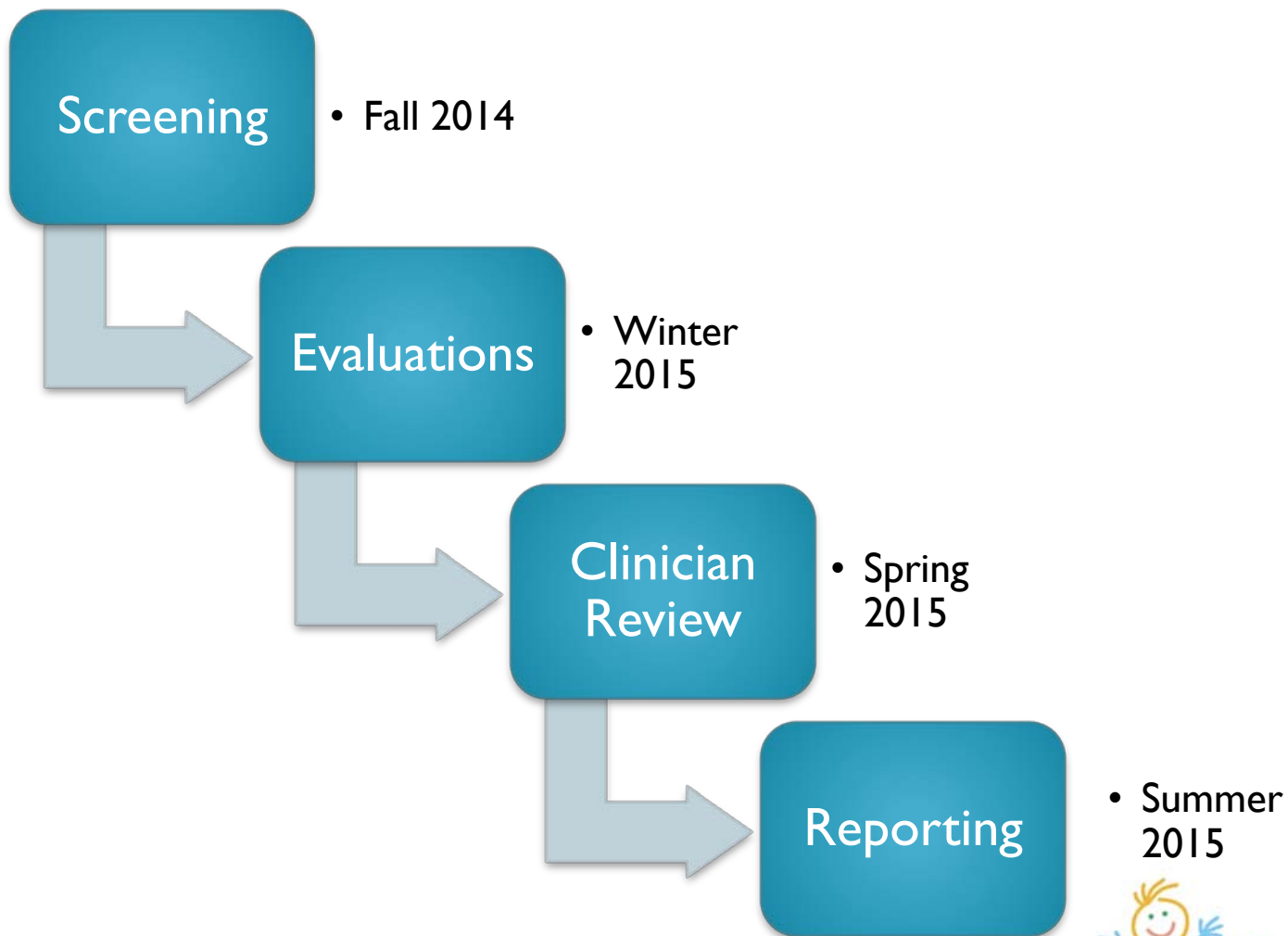




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Timeline



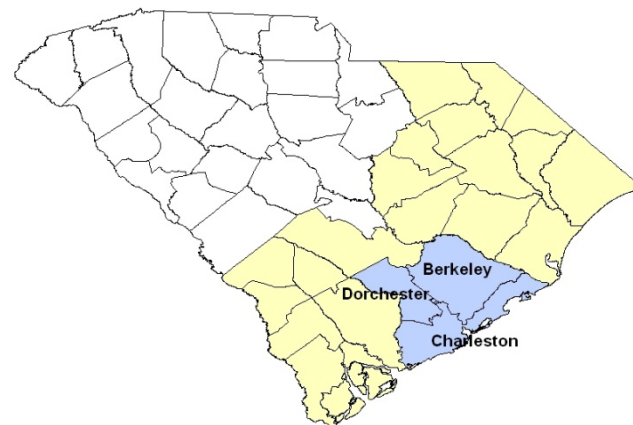


Characteristics of Study Area

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- 3 counties in SC
- Racially diverse
 - 59% White
 - 32% Black
- Lower ethnic diversity (7% Hispanic)
- Economically diverse
 - 33% schools with Title I status
- Rural and urban population
- High rate of illiteracy





Phase I: Screening

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- Goal: screen all children born in 2004 and living in target study area (n=8500)
- Social Communication Questionnaire (parent-completed)
- Distribution through partner schools, homeschool associations, and community events



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Screening Process

BEFORE

- *District level agreement*
- School level agreement
- Teacher meetings

DURING

- Introduction letter
- Screener (waiver of informed consent)
- Postcard reminder
- Last chance (*10% bump*)



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Partner Schools (106/134)

- Public Schools (73/85 completed)
 - 4 districts
- Private Schools (33/45 completed)
- Virtual Schools (0/3 completed)

-
- Home school associations (25)



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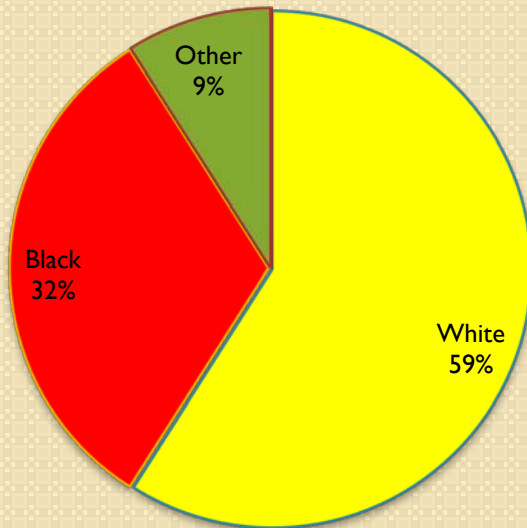
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Interim Data on Response Rate

- **Survey response rate to date = 51%**
- **Differential responding by race ($p < 0.0001$)**
 - White 46.3% (1167/2523)
 - Non-white 31.7% (749/2365)
 - *n=1515 with no racial information*
- **Differential responding by ethnicity ($p=0.5$)**
 - Hispanic/Latino 39.5% (166/420)
 - not Hispanic or Latino rate of 41.2% (1130/2741)
 - *n=3242 with no ethnic information*

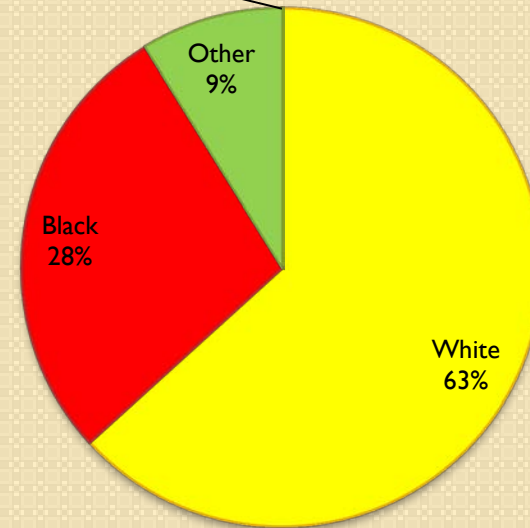
RESPONSE RATE COMPARED TO STUDY AREA CHARACTERISTICS

Racial Distribution of Study Area



Racial Distribution of Participants
0%

Racial Distribution of Participants





Community Events

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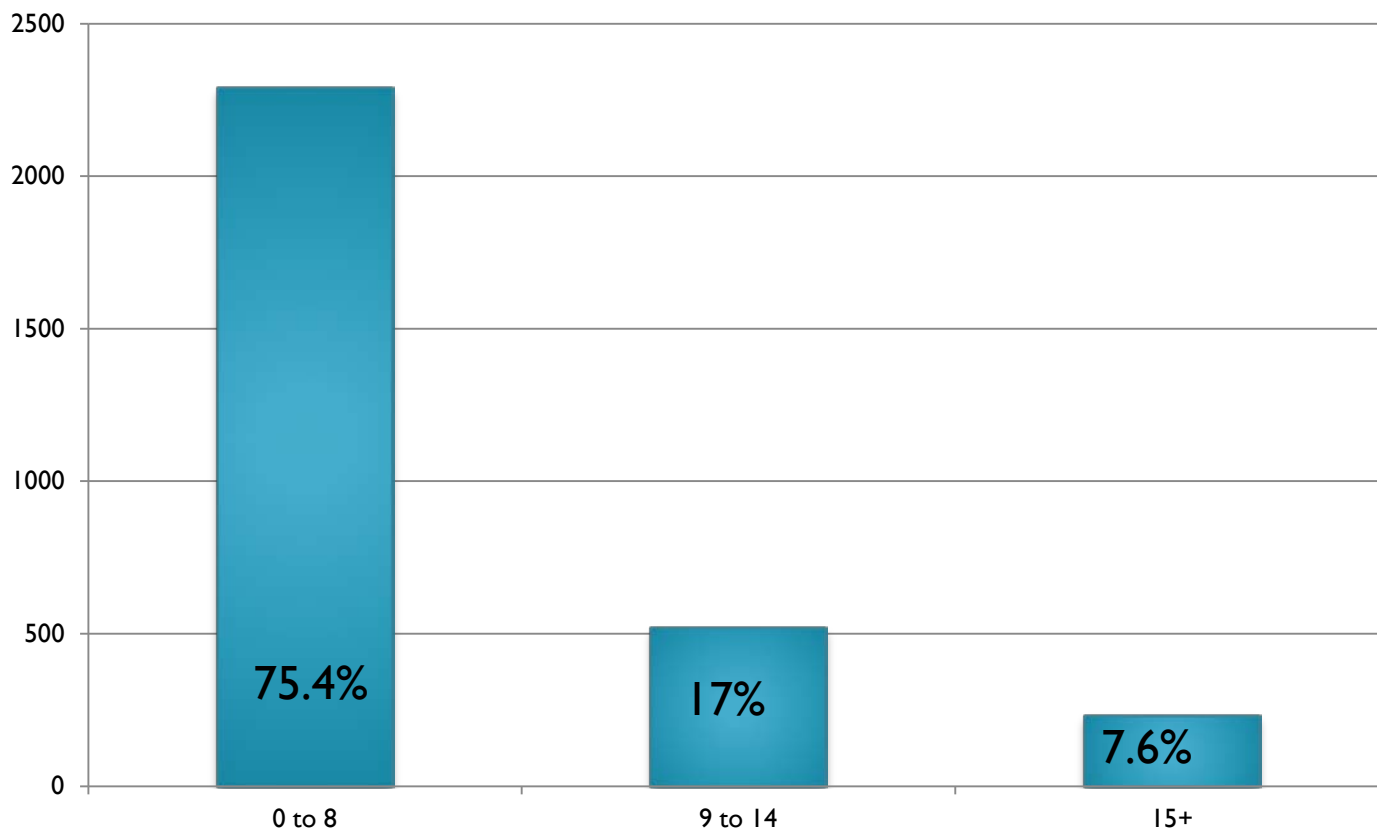




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SCQ Scores in General Population of 8-9 year olds (n=3031)





Suspected screening issues

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Table 2. SCQ-identified risk for ASD (SCQ 15+), and overall SCQ score

	At Risk N(%)	Not at Risk N(%)	p-value	SCQ Score Mean (SD)	p-value
Gender					
Male (n=730)	69 (9.5%)	661 (90.5)	0.009	6.5 (5.8)	<0.0001
Female (n=768)	45 (5.9%)	723 (94.1)		5.1 (5.0)	
Race					
White (n=902)	51 (5.7%)	851 (94.3%)	0.0002	4.6 (4.0)	<0.0001
Non-white (n=504)	56 (11.1%)	448 (88.9%)		8.0 (5.5)	
Ethnicity					
Hispanic (n=130)	24 (18.5%)	106 (81.5%)	<0.0001	8.7 (6.0)	<0.0001
Non-hispanic (n=957)	66 (6.9%)	891 (93.1%)		5.7 (5.3)	
Title 1 status					
Title 1 (n=475)	70 (14.7%)	405 (85.3%)	<0.0001	8.7 (5.8)	<0.0001
Not Title 1 (n=1022)	44 (4.3%)	978 (95.7%)		4.5 (4.8)	



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Phase 2: Clinical Evaluation

- At risk for ASD (SCQ = 15+)
 - 100% (n≈325)
 - About 50% agree to participate
- Elevated SCQ (SCQ = 9-14)
 - 20% (n≈150)



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Clinical Evaluation

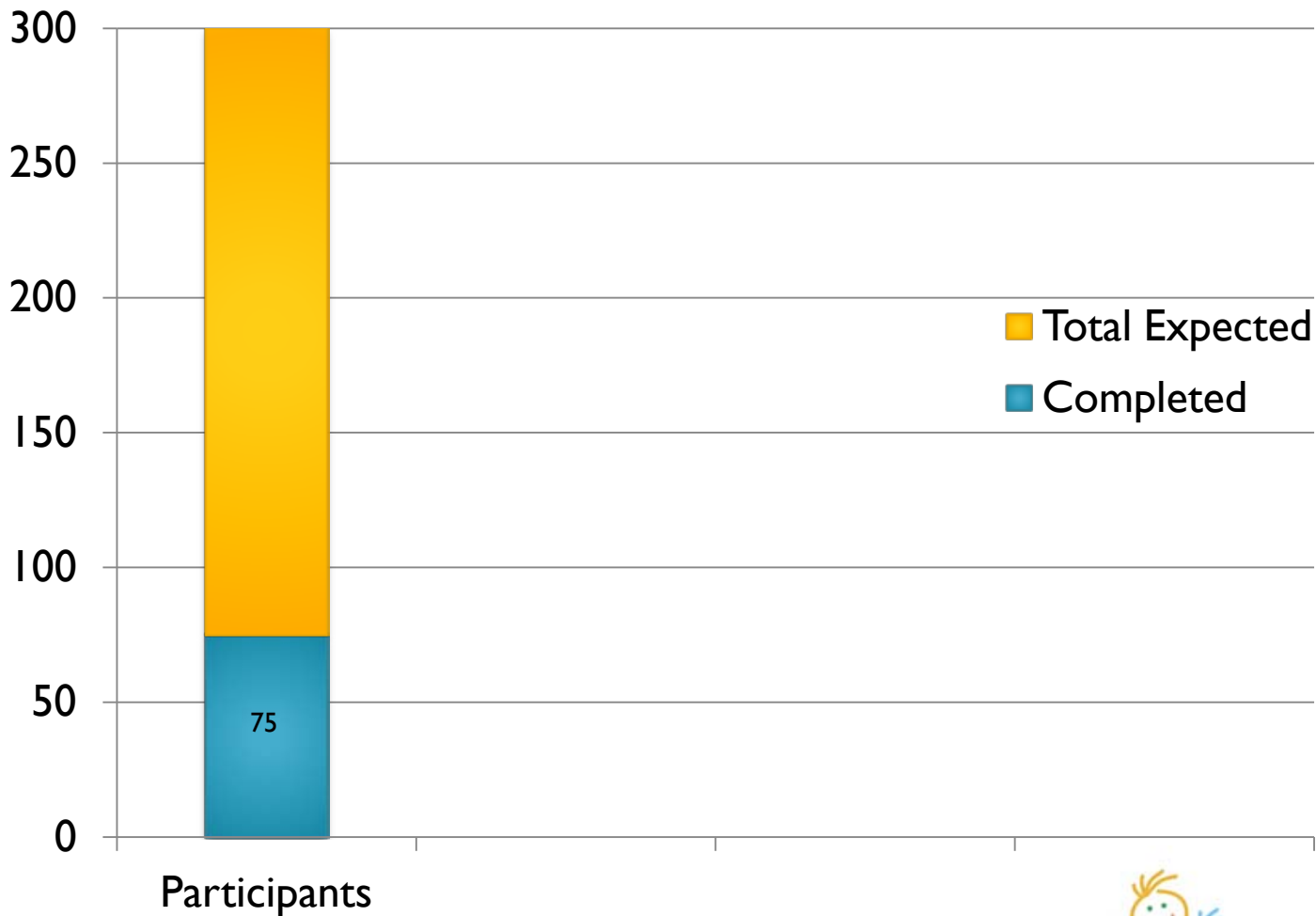
- Doctoral level clinical psychologists
- 3 hour assessment battery
 - Child
 - ADOS-2
 - Kaufman Brief Intelligence Test, Second Edition
 - Parent
 - DSM-neutral parent interview
 - Children's Communication Checklist
 - Vineland Adaptive Behavior Scales, Second Edition
 - Child Behavior Checklist (parent and teacher)
 - Social Responsiveness Scale – 2 (parent and teacher)



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Progress





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Community-engaged research

1. Start at the top
2. Use foot in the door technique
3. Have professional materials and strong follow-through
4. Pilot materials and incentives
5. Anticipate significant IRB work
6. Use a community advisory board
7. Hire people with good social skills
8. Consider barriers specific to your community
9. Be visible in your community



SUCCESS UPDATE

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SUCCESS has been in progress since January of 2012. The study aims to better understand how many children are affected by Autism Spectrum Disorders (ASD), and to understand how prevalence might change based on how ASD is defined. SUCCESS uses a population-based screening and assessment methodology to determine the prevalence of ASD. This means that the

team attempts to screen all children in a specific target area. In this case, children born in 2004 and living in Dorchester, Berkeley, and Charleston Counties are eligible. Following the screening process, about 10% of children are invited into the clinic for a free developmental assessment. The results of these assessments are used to calculate overall prevalence of ASD.

March, 2014

Where have we been?

- ✍ Berkeley County Public Schools
- ✍ Charleston County Public Schools
- ✍ Dorchester 4 Public Schools
- ✍ Many Private Schools

Where are we going next?

- ✍ Dorchester 2 Public Schools
- ✍ 13 Private Schools
- ✍ 24 Homeschool Associations
- ✍ 4 Virtual Schools

"Every Child Counts!"

SUCCESS Families and Teachers are Winners



Prizes and rewards help to keep our families and teachers excited about the study. Since the study began, we have given away over \$2500 to teachers who have helped with our study by distributing surveys, encouraging participation, and completing questionnaires. We've also given 6 iPads, 10 iPod Touches, and many gift cards to families that have volunteered. "It's been fun to call families to let them know that they have won a prize. One round of iPads and iPod touches went out right before the holidays and families were so excited to have an unexpected gift under the tree," said Catherine Bradley, PhD, SUCCESS Psychologist.



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Screening and Assessment Studies

- Diagnosis confirmed using gold-standard assessment tools and highly trained clinicians
- Prior diagnosis of ASD not required
- Rich information about cases



Limitations

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- Participation affected by how you market the study
- Participation affected by attitudes towards ASD
 - Awareness of symptoms
 - Access to services and assistance
 - Beliefs about ASD
- School aged diagnosis is not the same as infant/toddler diagnosis
 - DSM IV vs 5



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QUESTIONS/DISCUSSION