HRPP: 161892



INFORMATION SHEET

Adapting and Implementing an Integrated Care Model for Youth with Autism Spectrum
Disorder and Psychiatric Comorbidity (Caregivers)

SPONSOR: National Institutes of Health INVESTIGATOR: Nicole Stadnick, PhD, MPH

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You are being invited to participate in a focus group with 2-8 other caregivers. The purpose of this informational sheet is to provide you with information about this study.

- The purpose of this new study is to improve identification of mental health problems and linkage to mental health care for children with autism spectrum disorder (ASD).
- You are being asked to take part in this study because you are the caregiver of a child with autism spectrum disorder (ASD). As part of our investigation of how to improve identification of mental health problems and linkage to mental health care for children with ASD, we are conducting focus groups with caregivers. These focus groups will take place at a convenient location and time.
- ➤ Participation in this study is entirely voluntary. You may choose not to be in this study. Your decision to participate will not affect any benefits or medical care you receive.
- ➤ The focus group with 2 8 other caregivers will last approximately 1 hour.
- You will be asked to discuss your perceptions of the following: mental health needs of children with ASD served in primary care, comfort discussing mental health in primary care appointments, current procedures for mental health screening and linkage to evidence-based mental health care, and ability and need to modify current procedures for children with ASD.
- ➤ The session will be audio-recorded. We will transcribe the recordings and study the transcripts. When we transcribe the audio recordings we will not include any names or other identifying information.
- You can share only what you feel comfortable sharing, and you can refuse to answer any question. All information will be kept strictly confidential.
- There are minimal risks if you participate in this study. Some of the questions may be considered sensitive, may be difficult to answer, or may cause uncomfortable feelings. You may refuse to answer any question.
- ➤ There is no guarantee that you will directly benefit from participating in this study. However, results from this research has the potential to benefit implementation of improved mental health screening and referral processes in pediatric primary care for children with ASD. If you complete the entire focus group you will receive a \$40.00 gift card.

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The information we collect will be shared only with the research team and will be kept strictly confidential.

When we report the results of this work, we may include quotations. We will never give the name or any other identifying information of the person we are quoting. We may use some of the text from the transcripts of the audiotapes for scientific meetings or educational purposes. If we do, we will only identify you as a participant or as a particular category of person (e.g., student, man, nurse, etc.)

If you have any questions about this study please contact:

Nicole Stadnick, PhD, MPH Principal Investigator University of California, San Diego (858) 966-7703 x7101; nstadnic@ucsd.edu

If you have any questions about your rights as a research subject, please contact:

University of California, San Diego Human Research Protections Program (858) 246-4777

