Participant Information Sheet for the
Survey to Promote Resources and Opportunities for Autistic Teens and young adults (SPROUT)

You participated in the Study to Explore Early Development (SEED) when your child was between 2 to 5-years old. SEED was designed to help people with and without autism. You may have also participated in SEED Teen or the SEED Follow-Up Study. We'd now like you to complete a brief follow-up survey about your child's health and healthcare needs so we can learn how to support different people as they grow older. The survey should take between 10 and 30 minutes to complete. You'll receive a $30 digital gift card to thank you for your time. All of your answers will be kept private. More details are provided below.

You can follow this link to complete the survey now: <*add link*>. You can also call <*enter site phone number*> for more information.

What is the purpose of SPROUT?
This survey will help us better understand the health and healthcare needs of people with and without autism and their families as they become adolescents and young adults. We are collecting data on topics including mental health and medical conditions like anxiety and sleep disorder. Other topics include ways to improve healthcare and understanding resources available to students as they transition out of high school.

Who is conducting the survey?
SPROUT is funded by the Centers for Disease Control and Prevention (CDC). Staff from the CDC and their partners from seven sites located in California, Colorado, Maryland, Missouri, North Carolina, Pennsylvania, and Wisconsin are working together to conduct the survey. CDC and their partners value learning from the experiences of people with autism and other developmental disabilities. Your data and the information you provide can help us better understand the health and healthcare needs of people with autism compared to people without autism across the lifespan.

Why am I invited to participate?
You are invited to participate in SPROUT because you participated in a project called the Study to Explore Early Development (SEED) when your child was 2 to 5-years old. SEED included children with and without autism. By including people with and without autism, we can better understand the health and healthcare needs of different types of people. You and your family may have also participated in SEED Teen or the SEED Follow-Up Study. SPROUT is the newest version of these projects and was funded so that we can continue to learn about people with and without autism as they grow up. Some of the children who participated when they were young may now be 18 or older. If your child is 18 years of age or older, we will ask you to share their contact information with us. We are going to reach out to these young adults to invite them to share their experiences with us as well.

What will I be asked to do?

You will be asked to complete a survey about your child's health and development that will take between 10 and 30 minutes to finish. You can complete the survey online via a weblink or over the phone with a study team member.

Will it cost me anything to take part in SPROUT?
There are no costs to participate in SPROUT.

Will I receive anything if I take part in SPROUT?
You will receive a $30 digital gift card after you complete the survey to thank you for your time. If your child participates when we reach out to them, they will also receive a $30 digital gift card for their time.

What are the possible benefits of taking part in SPROUT?
The benefit of participating in SPROUT is the opportunity to share your personal experiences. Your voice matters and information that you share will help us learn how to better support people with and without autism and their families.

Are there any risks involved with SPROUT?
There is little risk involved with taking part in SPROUT. You may feel nervous answering some questions because they are sensitive in nature. You are free to skip any question(s) that you do not want to answer or that make you uncomfortable.

Will my information be kept private?
Any information that you give us will be kept private. Only SPROUT staff will be able to look at the information you provide.

Your personal information will be stored on a secure server at the site where you enroll. Your name and contact information will not be shared with anyone. The information you give will always be combined with information from other participants in reports. We will never share information that can identify you individually or as a SPROUT participant.

Do I have to take part in SPROUT?
It is your decision whether to take part in SPROUT. You are free to skip any questions that you do not want to answer or that make you feel uncomfortable. We ask that you complete as much of the survey as possible so we can use the most complete information available.

How can I withdraw from SPROUT?
You can withdraw from SPROUT at any time. If you wish to withdraw, please call <*site phone number*> or email <*site email*>. If using email, please include "SPROUT Withdraw Request" in the subject line.

Will I be told about the results of SPROUT?
We will send you a project newsletter up to two times per year. You can sign up for it here: <*add link*>. The newsletters will provide updates on the project and information that may be relevant to you and your child's healthcare needs.

To learn more about SEED research findings so far, please visit our website: SEED Research Findings | Autism Spectrum Disorder (ASD) | CDC.

Who can I call if I have questions about SPROUT?
If you have questions about the project in general, or if you would like to schedule an appointment to complete the surveys over the telephone, you can call <*site phone number*>.

We hope that you will help us with this important project. Your voice matters and could improve healthcare for different types of people. Thank you for considering this request.