

## DATA COLLECTION FLOW OUTLINE

### **Abbreviations:**

**CASE** – Autism Spectrum Disorder - Case Group,

**DD** – Developmental Delay or Disability

**POP** - Randomly sampled population Comparison Group

The following study flow charts will be included in the Enrollment Packets sent to the mothers of children in the ASD, DD, and POP workflows as determined during the Invitation Call

All study participants will be assigned to one of three workflows that will determine the data collection study protocol:

1. ASD workflow (also known as POSSIBLE ASD workflow):
  - a. All children who are identified from data sources as having a previous ASD diagnosis and/or autism special education eligibility;
  - b. All children identified as having a previous ASD diagnosis during the invitation call (including children originally ascertained from lists of potential DD or POP participants);
  - c. All children who screen “positive” on the SCQ screen – defined as SCQ score =>11 (including children originally ascertained from lists of potential DD or POP participants).
2. DD workflow: children identified from sources as having one of the DD diagnoses or special education eligibilities included in the “broad net” list who:
  - a. Do NOT have a positive ASD screen: SCQ score <11; and
  - b. Do NOT have a maternal report of a previous ASD diagnosis.
3. POP workflow: children randomly sampled from birth records who:
  - a. Do NOT have a positive ASD screen: SCQ score <11; and
  - b. Do NOT have a maternal report of a previous ASD diagnosis.

All families will be sent the study flow charts at two different points in the study:

- Enrollment Packet (mailed after the Invitation Call and in advance of the Maternal Interview)
- Forms Packet (mailed after the Maternal Interview).

Different sections of the form will be highlighted in the two mailings to indicate to the participant what study step she is currently completing and what the next step will be.

Different sites may use slight variations of this form. For example, these forms have been developed to include the possibility of a home visit in addition to a visit at the study site clinical location. Not all sites will offer home visits and the study flow chart verbiage will be adjusted accordingly.

## Attachment 18

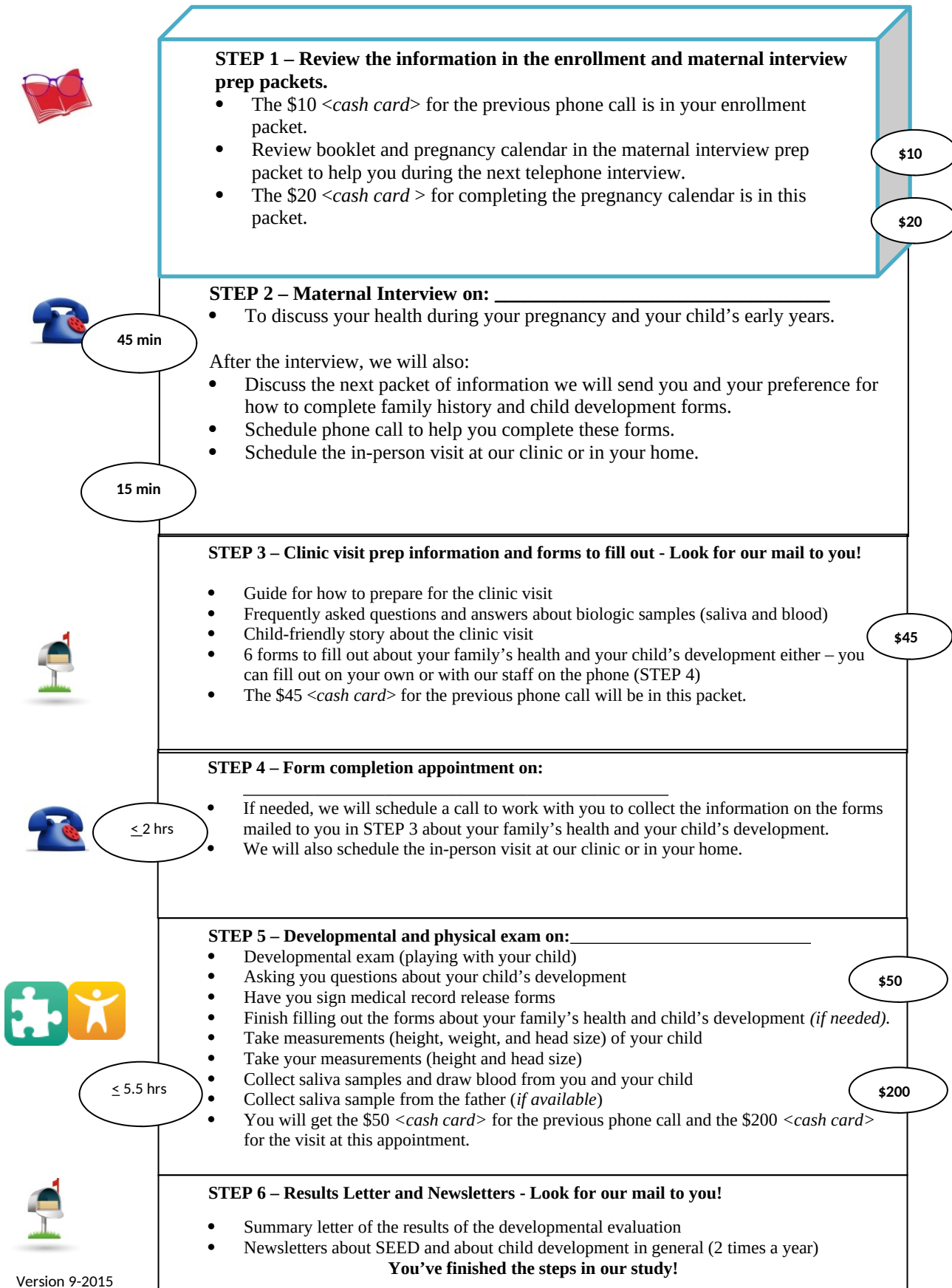
## ASD Workflow Study Flow Chart (first mailing)

<b>GROUP: ASD</b>			
	<b>Data Collection Step*</b>	<b>Time to Complete</b>	<b>Time Incentives</b>
1	Invitation Letter		
2	Screening and Invitation Phone Call (with the SCQ)	30 min.	
3.	Enrollment Packet (includes incentive for the eligibility screening)		\$10
4.	Follow Up Phone Call 1 (includes completing Pregnancy Reference Form)	15 min	\$20
5.	Maternal Interview Call	60 min	\$45
6.	Clinic Visit Preparation, Medical History and Child Development Forms Packet	95 min	\$50
7.	Follow Up Phone Call 2 (includes answering questions, help with self-administered forms as needed, and preparation for clinic visit)	20 min	
11.	Clinic/Home Visit	330 min	\$200
	<b>TOTAL</b>	<b>9 hours, 10 minutes</b>	<b>\$325</b>

*\*refer to study flow diagram for details*

## What Study Step Are You At?

Keep this sheet handy. It outlines the steps in SEED and you can fill in your appointment times. Each step builds on each other and is voluntary.



## Attachment 18

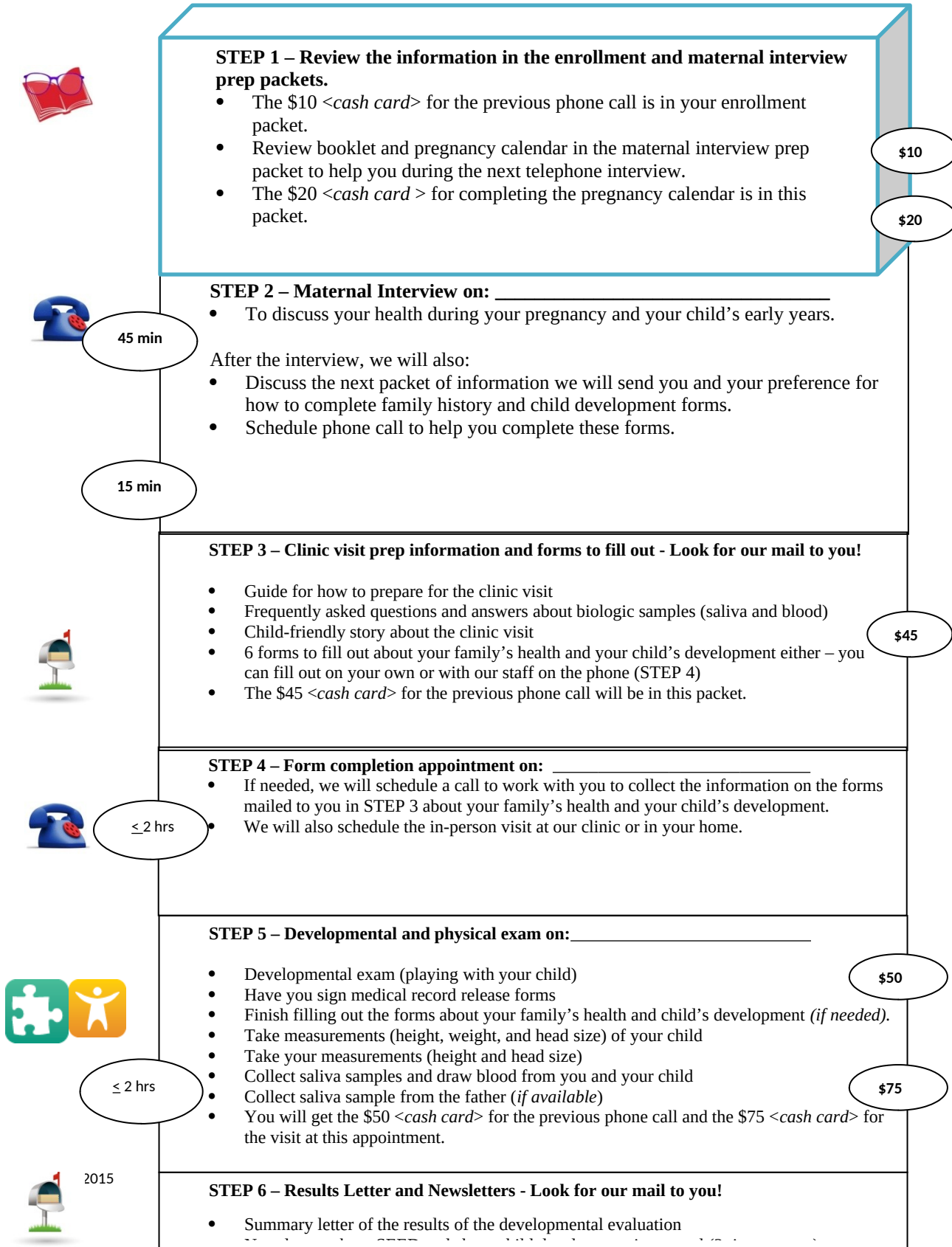
## POP Workflow Study Flow Chart (first mailing)

<b>GROUP: POP</b>			
	<b>Data Collection Step*</b>	<b>Time to Complete</b>	<b>Time Incentives</b>
1.	Invitation Letter		
2.	Screening and Invitation Phone Call (with the SCQ)	30 min.	
3.	Enrollment Packet (includes incentive for the eligibility screening)		\$10
4.	Follow Up Phone Call 1(includes completing the Pregnancy Reference Form)	15 min	\$20
5.	Maternal Interview Call	60 min	\$45
6.	Clinic Visit Preparation, Medical History and Child Development Forms Packet	95 min	\$50
7.	Follow Up Phone Call 2 (includes answering questions, help with self-administered forms as needed, and preparation for clinic visit)	20 min	
11.	Clinic/Home Visit	110 min	\$75
	<b>TOTAL</b>	<b>5 hours, 30 minutes</b>	<b>\$200</b>

\*refer to study flow diagram

## What Study Step Are You At?

Keep this sheet handy. It outlines the steps in SEED and you can fill in your appointment times. Each step builds on each other and is voluntary.



Attachment 18

DD Workflow Study Flow Chart (first mailing)

GROUP: DD			
	Data Collection Step*	Time to Complete	Time Incentives
1.	Invitation Letter		
2.	Screening and Invitation Phone Call (with the SCQ)	30 min.	
3.	Enrollment Packet (includes incentive for the eligibility screening)		\$10
4.	Follow Up Phone Call 1 (includes completing the Pregnancy Reference Form)	15 min	\$20
5.	Maternal Interview Call	60 min	\$45
6.	Medical History Forms Packet (4 forms only)	60 min	\$50
	<b>TOTAL</b>	<b>2 hours, 45 minutes</b>	<b>\$125</b>

\*refer to Appendix H. for detailed study flow diagram

## What Study Step Are You At?

Keep this sheet handy. It outlines the steps in SEED and you can fill in your appointment times. Each step builds on each other and is voluntary.



### STEP 1 – Review the information in the enrollment and maternal interview prep packets.

- The \$10 <cash card> for the previous phone call is in your enrollment packet.
- Review booklet and pregnancy calendar in the maternal interview prep packet to help you during the next telephone interview.
- The \$20 <cash card > for completing the pregnancy calendar is in this packet.

\$10

\$20



45 min

### STEP 2 – Maternal Interview on: \_\_\_\_\_

- To discuss your health during your pregnancy and your child’s early years.

After the interview, we will also:

- Discuss the next packet of information we will send you and your preference for how to complete family history and child development forms.
- Schedule phone call to help you complete these forms.
- Schedule the in-person visit at our clinic or in your home.

15 min

### STEP 3 –Forms to fill out - Look for our mail to you!

- 4 forms to fill out about your family’s health – you can fill out on your own or with our staff on the phone (STEP 4)
- The \$45 <cash card> for the previous phone call will be in this packet.

\$45



≤ 2 hrs

### STEP 4 – Form completion appointment on: \_\_\_\_\_

- If needed, we will schedule a call to work with you to collect the information on the forms mailed to you in STEP 3 about your family’s health and your child’s development.



### STEP 6 – Thank you Letter and Newsletters - Look for our mail to you!

- Thank you letter
- The \$50 <cash card> for completing the health history forms will also be included.
- Newsletters about SEED and about child development in general (2 times a year)

\$50