

Table 2: Protocols to Assure Assent and Consent are Voluntary

Likely Circumstances When People have an ID/DD	Protections
<p>One possible situation that may arise is that a student with an intellectual disability wants to participate in the study but may have difficulty giving a clear yes response. Students who give assent to participate typically have a personal reason for deciding to participate. They may or may not be able to express that thought. When they decide to participate they generally attempt to say yes that they want to try the website and be in the study. At the same time, they will also show signs of positive affect that are consistent with a yes response. These signs may include: Smiling, reaching for a pen to sign, asking questions to show interest, nodding their head up and down, pointing to a word or icon for yes or no. Finally, when the opportunity to engage in the activities of the study actually happens; students who want to participate will continue to do so.</p>	<ul style="list-style-type: none"> • Investigators will introduce themselves and communicate briefly to establish rapport. • Information will be presented in short sections in both verbal and visual formats so that it is easier to absorb and understand. • Attempt to obtain assent will be made after each section of information is presented. • Investigators will observe whether the person indicates they want to participate in the study. • Investigators will observe whether the person shows signs of positive affect consistent with a decision to participation. • Participants will confirm their interpretation of the person’s statement of assent with a familiar person who can state how they know the person actually means yes. • Investigators will ask yes/no questions to confirm that assent is being given and is voluntary.
<p>A second possible situation is that the student clearly assents to participate but is doing so primarily as a learned responses to authority figures: Students with ID/DD are more likely to agree to participate because they think it will please the investigator or they might be in trouble if they say no. Students will typically show affect that does not match a yes decision when they are do not really want to be involved but don’t want to say no. These behaviors may include: Shaking their head no while saying yes, hesitating a long time, prevaricating with phrases like “Well, I don’t know, “ frowning, giving reasons why participation might not work for them, shutting down, or making statements that show pleasing the researcher is important or not participating means the researcher will be disappointed. Students with ID are also more likely to say no to a new opportunity that is not familiar and it can be difficult for a researcher or familiar</p>	<ul style="list-style-type: none"> • Teachers and investigators will avoid attempts to influence the student’s decision by any overt means. • Teachers and investigators will avoid using voice controls when speaking to students about the decision (overly familiar, cajoling, authoritarian tone of voice,). • Students will be informed that a no response is as good as a yes response. • Students will be reminded that even after they say yes to try the website, they can stop at any time. • Students will be provided with both the benefits and the risks involved in participation. • Students will not be reminded of their parent’s decision that they can participate. • Students will be shown a “story” (oral and print format) of a person who decided to participate

<p>teacher not to pressure a student who has a learned pattern of saying no without considering the information.</p>	<p>and a person who decided not to participate. In both stories the student's decision will be reinforced.</p> <ul style="list-style-type: none"> • Students will be encouraged to think about what they want and not to base a decision on what they think the interviewer wants.
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<p>A third possible scenario is that the student decides not to participate and their no response is either not clear or not taken seriously. The student may shake their head no, say no, refuse to sign the form, leave the room, shut down or ask to be left alone, complain, act out or otherwise demonstrate a non-yes response.</p>	<ul style="list-style-type: none"> • Students will be helped to verbalize a possible no response "It sounds like you would rather not be in the study." • Investigators will not attempt to explain or prolong the interview unless the student has asked a specific question. • Teachers will not be able to explain further or attempt to persuade the student further.
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