

ANGELMAN SYNDROME VINELAND-3 ADMINISTRATION MANUAL

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Introduction

The Vineland Adaptive Behavior Scales, Third Edition (Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2016). *Vineland adaptive behavior scales*, Third edition (Vineland-3). Bloomington: NCS) caregiver interview is a standardized assessment used to measure functional day-to-day skills of individuals from birth through 90 years of age. The Vineland-3 interview form is completed by a trained professional who interviews a parent or caregiver about the adaptive behavior of the individual. The Vineland-3 assesses an individual's abilities in five subdomains: Communication (inclusive of expressive, receptive, and written communication skills); Daily Living (inclusive of self-care, care of the home, and navigation in the community); Socialization (including interaction skills, play/managing activities of enjoyment, and adaptability); Motor Skills (gross and fine motor) and Maladaptive Behavior. Standard scores are available for all individuals for Communication, Daily Living, and Socialization subdomains and for individuals aged 9 years or younger for the Motor subdomain. Navigation through the Vineland-3 caregiver interview allows for reflection from the caregiver on observed presentation, rather than yes or no response options as to whether skills are present. An open-ended question or prompt is provided, with scoring based on caregiver response.

Because individuals with Angelman syndrome (AS) present with substantial developmental delays, a standardized measure of adaptive skills is critical to better understanding independence, functionality, and a proximal measure of cognitive ability. This manual provides AS-specific guidance for administration of the Vineland-3 to caregivers of those with AS in research and clinical trial settings, as informed by long-term administration of this measure in clinical experience and natural history studies.

Guidance provided in this manual is not meant to provide modifications to the standardized instrument; rather, it is to provide suggestions for how to manage common questions or difficulties in administration and scoring of specific items specific to individuals with AS.

Manual Development

The recommendations and accommodations suggested in this manual were developed through a comprehensive systematic procedure, including in-depth interviewing of active clinical and research administrators, item-level review, and meetings with an expert on Vineland-3 administration procedures.

Summary of Interviews. Structured interviews were conducted with nine professionals who had experience administering the Vineland-3 to caregivers of clinical trial participants with AS. Interviews focused on gathering information regarding challenges and barriers to successful administration and items that the raters found more difficult to administer or score specifically for individuals with AS.

Summary of Item Review. Every item on each domain across the Vineland-3 was reviewed by at least two experts in psychological assessment and AS, and any concerns regarding how an item might be administered or scored were noted, as were suggestions for how to make the item clearer with regard to intent (determined through review of the Vineland-3 manual).

Summary of Meeting with Expert Trainers. Findings from the interviews, along with the item analysis, were shared with expert trainers, Celine Saulnier, PhD—ADD MORE ABOUT HER—and Audrey Thurm, PhD—Director, Neurodevelopmental and Behavioral Phenotyping Service, Intramural Research Program, National Institute of Mental Health. Final recommendations for item clarity were determined. Consideration for staying within the established parameters of the tests was prioritized, as were allowable accommodations or clarifications to assist with standardized instructions for raters and AS-specific needs.

This effort resulted in intentional and critical guidelines that should be followed as closely as possible to ensure standardized administration. The following recommendations are for the Comprehensive Caregiver Interview Form for the Vineland-3, which can be administered either via paper-pencil format or via Q-Global, an online administration tool.

Examiner Considerations

Administrator Qualifications

- Assessors with graduate-level training or courses in child development and testing and measurement AND work experience with patients with AS or similar phenotypes.
 - Education: BS/BA or higher
 - Prior scale experience: Minimum of 15 prior administrations of Vineland AND
 - Minimum of 3 years of experience working with individuals with AS or similar phenotypes in clinical or research settings
 - Routinely supervised by individuals with a graduate degree.
 - Education: MD/DO/PhD/PsyD
 - Prior scale experience: Minimum of 10 prior administrations of Vineland AND
 - Minimum of 2 years of experience working with individuals with AS or similar phenotypes in clinical or research settings
- An understanding of typical developmental trajectories and behavior is of high utility when administering the Vineland
- Experience working with caregivers of individuals with significant developmental delays, AS, or disorders with similar phenotypes
- Administrator qualifications should be documented as part of trial-related materials (e.g., CV on file).

Training Procedures

The following steps should be taken by all administrators before assessing a patient or participant.

1. Review the Vineland-3 administration manual and this AS-specific training manual.
 - a. Familiarize self with best practices in interviewing
 - b. Ask open-ended questions to caregiver: *How does he....? Tell me about....What does he do for..? How does he...?*
2. Avoid close-ended or Yes/No questions: *Does he...? Will she...?*
3. Review training videos created for AS clinical trials (Coming)
4. If the assessor has not administered the Vineland-3 previously
 - a. Roleplay a full assessment with at least five volunteers to achieve fluency and familiarity with determining scoring based on variable reporting.
 - b. If feasible, observe and double score an administration led by an experienced administrator.
5. All raters should submit recorded administration for feedback from centralized trainers (e.g., provided through Pearson, through a clinical research organization, or via expert consultants)
 - a. This submission should include a self-critique form and a scored protocol.
 - b. A *certified reviewer* will then complete a fidelity measure to provide certification for administration of the Vineland-3 in clinical trials for AS.
6. Annual retraining should happen through a review of an administration (live or via video) at least annually.
7. A listserv should be established for raters to use to get questions answered or to brainstorm how to score a specific item as needed.

Critical Guidance for Administration

Scheduling of Interview:

- Schedule up to 90 minutes with the caregiver to complete the interview.
- Schedule a time when the caregiver is available, will be fully present, and will not be distracted by competing demands.
- Ensure the same rater and caregiver complete the interview at repeat visits.
- Interviews should be conducted face-to face or by videoconference

Caregiver Participation

- Build rapport with the caregiver as their comfort with you will directly impact their fluidity and responsivity.
- Before beginning, ask the caregiver questions about the individual:
 - Tell us a little about [Name of individual]?
 - What do they like? How do they show that they're happy or calm? What sorts of things are important to know about them?
 - Where do they believe the individual is developmentally (e.g., motor, communication, learning, self-care)?
- Let the caregiver know the interview will take around 45–60 minutes. Take breaks as needed. The Vineland-3 can be completed over multiple sessions if the sessions are all completed within 1 week.

- Start by explaining the purpose of the interview:
 1. *“Learning about [Name of individual]’s adaptive behavior will help us gain a total picture of them. Adaptive behaviors are the day-to-day activities that are necessary for individuals to get along with others and take care of themselves. We would like to know how the participant typically behaves at home and to get a sense of all of the things they actually do independently without help or prompting, supports, or reminders. Consider what skills the **participant can actually do now or how they typically behaves**, not what they might be capable of doing. I will be asking about skills that are above and below [Name of individual]’s level to ensure that we capture their full range of skills.”*
- Emphasize the importance of honest answers; there are no right or wrong answers to the questions.
- Explain that you will be asking about four types of adaptive behaviors.
 1. **Communication**: How well the participant communicates (either through use of words or AAC, gestures/signs) and understands others or whether they can read or write
 2. **Daily Living Skills**: How well the participant takes care of him/herself, helps out at home, and functions in the community
 3. **Socialization**: How well the participant interacts with others, including acting appropriately toward other people
 4. **Motor Skills**: How well the participant uses their body, large muscles, hands, and fingers for everyday activities

General Recommendations for Clinical Trials

Guidelines for paper-and-pencil administration versus Q-Global:

- We recommend the use of the Q-Global web-based platform developed by Pearson as much as possible.
- Paper-and-pencil administration should be available as needed (e.g., in the event of internet outage or other technological issue).
- If paper-and-pencil administration is used, we recommend (1) a quality control process (review by an independent team member) to ensure all items have been administered and (2) indicating that the test was administered using paper and pencil rather than via Q-Global.

Method of Administration

- Face-to-face interaction with the caregiver is preferred (either in-person or via telehealth) and important for rapport.
- Use of just the telephone (without video) is not recommended.
- The Vineland-3 may be conducted remotely as needed to accommodate the needs of caregivers and study participants. The study protocol should indicate when remote assessments are allowed.

Repeat Administration

- The same rater or assessor should complete the repeat interviews.
- The same caregiver must be interviewed for repeat assessments.

Testing of the limits

- Individuals with AS may have achieved skills beyond the ceiling of Vineland-3 subdomains. It is important to capture that information.
- At the end of a subdomain, after the ceiling has been met, ask the caregiver whether there are there any skills associated with that specific subdomain that were not discussed and that they think are important about the skill of the individual with AS. For example, within the personal domain, if you have not asked about toilet training you can ask, “Where is he/she in terms of toilet training?”?
- The skills beyond the ceiling of the subdomain should be noted on a separate sheet.
- Information gathered here should not be considered in calculating subdomain scores.

The Maladaptive Behavior Subdomain

- The maladaptive behavior subdomain asks about psychiatric symptoms in typically developing population.
- The questions **are not appropriate** for individuals with significant developmental disabilities who are nonverbal. For example, questions are asked about masturbation, etc.
- We strongly recommend that the maladaptive behavior subdomain not be administered to individuals with AS.

Administration

Start Points

- For individuals with AS, start at **item 1** for all subdomains (start point 0 on Q-Global) This includes repeat administrations, which should also start at start item 1 for all subdomains.
- Please ensure that all subdomains required by the study are administered.

Basal/Ceiling Rules for Caregiver Interview Form

- For each subdomain, the basal is **4** consecutive items with a score of “2.”
- For each subdomain, the ceiling is **4** consecutive items with a score of “0.”
- Continue administering interview topics until a basal and ceiling for that subdomain have been established.
- If multiple basals or ceilings occur, use the *highest basal* and the *lowest ceiling* for calculating raw scores.
- If the respondent has not had the opportunity to observe a behavior, ask them to estimate a score for that item and then check the box labeled *Check if Estimated*.

Scoring Considerations

- Score based on what the individual can do independently without physical help or verbal prompting, supports, or reminders.
- Score the individual’s actual performance. Consider whether they do the activity rather than whether they can or cannot. Vineland-3 is a measure of APPLIED skills—the participant must do the activity independently.
- Items with “and” require that individuals need to complete all parts to get credit.

- “Or”...individual needs to complete one of these behaviors to receive credit.
- For the scoring of motor domains for children younger than 10 years, only note raw score, age equivalent, and GSV.
- Score based on how often an activity or item is performed when needed or appropriate.
 - 0: If an individual does not currently perform a behavior and never did it when younger
 - 1: When the behavior is needed or appropriate, the individual sometimes performs it independently without help or prompting
 - 2: When the behavior is needed or appropriate, the individual usually or always performs the skill independently without help or prompting (or the individual does not currently perform a behavior but did so when he/she was younger and has now outgrown the behavior)
- For each subdomain and domain, raw scores, age equivalents, and growth scale values can be calculated along with standard scores.