# Measures of Adaptive Behavior

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## History of Adaptive Behavior

*Defining* refers to describing the meaning and the exact limits of something. Before the development of the definition of intellectual disability (ID) by the American Association on Intellectual and Developmental Disabilities (AAIDD), the inclusion of adaptive behavior in the diagnosis of ID and the understanding of the limits in one person's functioning have a long history.

Going far back in time, Ancient Greeks left the first documented scripts on adaptive behavior and its relationship with ID. They introduced the word "idiot" to define someone who does not interact with other people and does not participate in community settings.

Both Greek and Roman societies used to think that a person who cares for his or her health and who is able to attend social activities could be defined as "normal." "Idiots" were despised and often killed, because they were considered a burden to the society (Barr, 1905).

During the Middle Ages, the social stereotype did not change; in fact, people with intellectual disorders were often used as jesters with the purpose to entertain aristocrats (History of Intellectual Disability, 2016). The condition was usually attributed to witchcraft.

Only in the Enlightenment period, the first changes of direction were observed. For instance, both Christian humanitarian and scientific studies helped to make the lives of people with ID more worthy to be lived. In the seventeenth century, Thomas Willis provided the first description of ID as a disease. Some European societies started to build up interventions and individualized instructions for people with such disorders.

Another step for the definition of ID was made by Locke (1689), who first distinguished between "idiots" and "madmen."

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In 1838, Itard published the first report of a 10–12 years old child with mental retardation. A hunter and his wife that afterwards decided to adopt him found this child, named the "Wild boy of Aveyron," in the woods; he was not able to understand and to express language. Every attempt to give him teachings seemed to be unsuccessful. For this reason, the psychiatrist Itard decided to take the wild boy with him in order to study his condition and try to improve his adaptive functioning. At the beginning, the child was unable to meet social norms, to be empathetic, and to learn rules, but thanks to the effort of Itard, the wild boy developed a simplified language and rudimental behaviors that allowed him to interact with other people. Itard taught him to use cutlery, to be politely seated, and to dress himself, demonstrating that adaptive behavior can be modified by environment and rehabilitation (Oakland & Harrison, 2008).

In the same year, Esquirol published a revolutionary book on mental retardation. He noted that different levels of severity can be observed in ID and that language skills may be a key to distinguish between pathological and normal cognitive levels. Furthermore, he pointed out the importance of using objective methods to measure cognitive functioning. In 1838, Seguin, Esquirol's student, opened a school for children with special needs. This initiated the establishments of more than 80 residential institutions around Europe and America.

In 1859, with the publication of "On the Origin of Species," Darwin opened the debate about the relative contribution of nature – biological inborn characteristics and nurture – environmental impact on the development of man's behavior (Darwin, 1859). What is important to remember about this controversy is the idea that species such as ours could change over time. Darwinians believed that ID was inherited.

Influenced by Charles Darwin's theory, his cousin the psychologist, Francis Galton, proposed selective breeding of humans to reduce ID. He was interested in mental testing and conducted many of the first surveys to measure cognitive functioning. He was also the one who coined the terminology "mental test".

In 1905, Alfred Binet produced the first standardized test to measure intelligence in children. Binet and his colleagues tried to differentiate between children who could and could not benefit from education (Binet & Simon, 1948). According to Binet, intelligence could be defined as a skill to cope with all the daily life demands. Even though still implicitly, adaptive behavior continued to be considered an important ingredient in intelligence's definition. During these years, the psychologists Binet and Simon produced the first standardized intelligence scale, known as "Binet-Simon Scale." In 1916, Lewis Terman revised this test, renaming it "Stanford-Binet Intelligence Scale" and introducing the concept of IQ (intelligence quotient), which was the ratio between mental and chronological age (Cianciolo & Sternberg, 2004). However, his conceptualization of IQ had different limits, such as it didn't allow clinicians to compare people of different ages.

Only with David Wechsler (1939), who introduced the Deviation Intelligence Quotient, those methodological problems will be solved, as the latter notion allows to evaluate the performance of a subject in comparison to individuals of the same and different chronological ages and to compare the results provided by different tools (Picone et al., 2006).

In parallel with the development of mental testing, the first supported associations began to be founded. In 1879, the United States formed the "Association of Medical Officers of American Institution for the Idiotic and Feebleminded," renamed "American Association on Mental Deficiency" in 1933 and later "American Association on Mental Retardation" (AAMR). In 2007, as the term "mental retardation" was increasingly been replaced by the less offending definition "intellectual disability," AAMR changed its name to AAIDD (Schalock et al., 2007). The latest name is used throughout this chapter.

Although adaptive behavior did not play a central role in the diagnosis of ID during the first half of the twentieth century, the importance of social competency, adaptability to environment, and ability to cope with daily life was never completely abandoned. Alternative measures to mental testing began to appear as early as 1916.

Doll (1927), Kuhlman (1920), and Porteus (1921) started to develop psychometric measures of adaptive behavior. Doll, for example, underlined that social inadequacy due to low intelligence was one of the main points of mental retardation. Doll claimed that since IQ tests were normed on the general population, they were unable to really predict how much a person deviated from others. For this reason, he introduced the Vineland Social Maturity Scale (VSMS) (Doll, 1936), a tool of 117 items measuring practical skills and social competence. VSMS was a caregiver-report instrument and was administrable only to children. However, it had different limitations, such as the assumption that a person who has acquired a skill will display that skill.

In 1939, the first edition of the Wechsler Scales (WAIS), named the Wechsler–Bellevue Intelligence Scale, was published by David Wechsler (1939). This test is currently on its fourth edition (WAIS-IV) released in 2008 by Pearson and represents the most used and reliable intelligence test in the world. What is interesting to notice is the definition that D. Wechsler gave to intelligence: *"Intelligence is the aggregate or global capacity of an individual to think rationally, to act purposefully and to deal effectively with his environment"* (1939). Wechsler himself underlined that it would be unreasonable to thinking that intelligence tests may be the only measure of intelligent behavior and other factors should be taken into account. Indeed, dissatisfaction with the IQ scores as the sole index in people with ID raised over the time.

The assessment of adaptive behavior was formally included in the diagnostic nomenclature of ID in 1959, when Heber claimed that performance on mental tests does not always correspond to the real one person's daily life functioning (Heber, 1959). He conceptualized adaptive behavior as a construct consistent of three main factors: practical, social, and conceptual skills.

This new acknowledgment created the need to develop standardized measures of adaptive behavior. In 1969, Nihira and colleagues published the "Adaptive Behavior Checklist," the first psychometric assessment instrument of adaptive functioning to be used together with standard intelligence tests (Nihira et al., 1993). This scale had two forms: one for people older than 12 and one for people younger than 12. Nowadays, its revised nomenclature is the AAMR Adaptive Behavior Scale.

Heber's classification was reaffirmed in 1983 by Grossman, who underlined the importance of adaptive behavior in the diagnosis of ID (for a better definition provided by Grossman, see section "Adaptive Behavior: Assessment"). Both Heber and Grossman recognized the multidimensionality of adaptive behavior and underlined the influence of sociocultural factors on one person's cognitive and adaptive functioning.

Nowadays, it is clear that adaptive skills are essential to survival. Two people can perform at the same level on standardized cognitive tasks, but can exhibit completely different adaptive behaviors to their environments; for this reason, adaptive skills should be always evaluated during ID assessment.

Adaptive behavior deficits have been included in the current official definition of intellectual disability provided by AAIDD (Luckasson et al., 2002, p.1):

**Intellectual disability** is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. The following five assumptions are essential to de application of this definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioral factors.

3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.

In addition to AAIDD, another system for classifying ID is the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5), which is published by the American Psychiatric Association (APA, 2013) and which criteria for the diagnosis of ID are as follows:

1. Deficits in intellectual functioning. This includes various mental abilities, such as reasoning; problem solving; planning; abstract thinking; judgment; academic learning; experiential learning. These mental abilities are measured by IQ tests.
2. Deficits or impairments in adaptive functioning. This includes skills needed to live in an independent and responsible manner. Limited abilities in these life skills make it difficult to achieve age appropriate standards of behavior. Without these skills, a person needs additional supports to succeed at school, work, or independent life. Deficits in adaptive functioning are measured using standardized, culturally appropriate tests.
3. These limitations occur during the developmental period. This means problems with intellectual or adaptive functioning were evident during childhood or adolescence. If these problems began after this developmental period, the correct diagnosis would be neurocognitive disorder. For instance, a traumatic brain injury from a car accident could cause similar symptoms.

It is important to underline that, with the publication of DSM-5, IQ scores have been replaced by level of adaptive behavior deficits as the criterion to establish the severity levels of ID. Actually, adaptive behavior is more salient than IQ in predicting the support needs of a person.

Comparing the DSM-5 definition of ID with the ones of the previous editions, it emerges how the last version encourages a more comprehensive view of the individual and emphasizes the importance of adaptive behavior. For instance, in contrast to DSM-IV, which needs impairments in two or more skill areas, the DSM-5 criteria require an impairment in one or more superordinate skill domains (e.g., conceptual, social, practical) (Papazoglou et al., 2014).

Throughout the past 50 years of definitions provided by AAIDD and APA (see APA, 2013; Luckasson et al., 2002; Papazoglou et al., 2014), the relevance of adaptive behavior raised edition after edition. A valid diagnosis of ID requires the clinician to integrate assessment of cognitive functioning and adaptive behavior. In fact, the definition of ID, going back more than 100 years to the present, confirms that both are essential in the classification of ID.

In conclusion, the definition of adaptive behavior has a long history. Today it can be conceptualized as the collection of conceptual, social, and practical skills that have been learned and are performed during daily life. This definition is a continuation of the attention given to adaptive functioning and social adequacy in the diagnosis of ID (Shogren et al., 2017).

At this moment, there are at least 200 adaptive functioning scales that have been used for diagnosis, research, and individualized programming purposes; however, very few have adequate norms and

reliability to diagnose ID in people with low IQ. For this reason, in the next paragraph only the principal standardized adaptive behavior instruments will be described.

## Adaptive Behavior: Assessment

Assessment of adaptive behavior plays a key role in the diagnosis of ID. Furthermore, it provides important information about planning of treatments not only in individuals with ID, but also in individuals with neurodevelopmental disorders.

Back in the 1970s, investigating adaptive behavior was meant to understand "*the effectiveness and degrees to which the individual meets the standards of personal independence and social responsibilities expected for his age and cultural group*" (Grossman, 1973, p.11). Personal autonomies (moving around, using money) and the ability to take care of themselves (cleaning oneself, getting dressed) and to manage home-life (cooking, cleaning the house, washing clothes) are some features of the dimension of personal independence. The ability to follow the rules, to manage the time, to attend social events, and to respect different social norms represents some features of the dimension of social responsibilities.

Considering all the activities and the skills referable to adaptive behavior, both in the DSM-5 (APA, 2013) and in the last three editions of AAIDD manuals (Luckasson et al., 2002; Schalock et al., 2010; Schalock & Luckasson, 2021), three domains have been identified.

1. *Conceptual domain*: it includes communication and academic skills. Referring to communication, both comprehension and language production should be considered.
2. *Social domain*: it includes relational, social skills, and socio-emotional self-regulation abilities.
3. *Practical domain*: it includes compliance with safety rules and daily life skills. In regard to the latter, personal care, health care, legal decision, and housework tasks should be considered.

Moreover, when we refer to adaptive behavior, we must consider some crucial features (Harrison, 1990; Barclay et al., 1996, Sparrow et al., 1984). The adaptive behavior has the following characteristics:

(a) *Age-specific*: it develops in the first years of life, becomes more complex in adulthood, and then may face a decline in geriatric age. Furthermore, some behaviors can manifest and be adaptive at one age and not be it in other age ranges. For example, for a child, asking the mother to be accompanied to the bathroom is an adaptive behavior in the first years of life while it is no longer so when he/she is older.

(b) *Context-specific*: it is closely dependent on the demands of the environment in which the individual lives. Expectations about adaptive behavior are influenced by:
   - The different cultural/geographical group to which one person belongs.
   - The different contexts: conceptual, social, and practical abilities are not only expressed at home with caregivers but also with teachers, friends, and unknown people to relate to for various reasons (e.g., call a doctor's office to make an appointment). An evaluation of adaptive behavior in different contexts like home and school is recommended.

(c) *Concrete manifestation*: adaptive behavior must reflect the typical performance of the individual, not its best performance nor the performance he could hypothetically put in place if there was the opportunity.

(d) *Modifiability:* adaptive behavior can worsen or improve based on several factors including environmental changes or habilitation/rehabilitation programs.

Only through an accurate evaluation, that considers the different domains (conceptual, social, and practical) and different features of adaptive behavior, the clinician understands the exact functioning of the individual.

How is it possible to accurately assess adaptive behavior? Over the years, the scientific scene has tried to answer some questions concerning the methodological aspects of the evaluation of adaptive functioning:

1. *How should the evaluation be carried out? Directly or through third parties?*

Currently, the scales for measuring adaptive functioning involve interviewing the caregiver. Some exceptions provide a self-assessment by the individual (see ABAS-2 16–89 years "self-rating," Harrison & Oakland, 2003), but especially in cases of ID, it cannot be considered for diagnosis purposes. For the same reasons, the advantage of an indirect assessment also consists in measuring adaptive behavior even in cases of severe or profound ID, in which direct assessment is very difficult.

2. *Is it preferable to use one or more sources of information?*

As seen above, one feature of adaptive behavior is that it is context-specific. For this reason, having multiple sources of information (home, school, work) allows you to delve deeper into the functioning of the individual (Tassè et al., 2012, 2016).

3. *Is it necessary to have a global adaptive functioning score or different domains' scores?*

A profile that considers the different domains allows you to have a more specific picture of the functioning of the individual, of his strengths and weaknesses. This is important both for an accurate diagnosis of ID (criterion B of Diagnostic and Statistical Manual fifth edition, DSM-5 Manual; APA, 2013) and for planning targeted interventions.

These characteristics discussed above should be present in the main tools for assessing adaptive functioning.

Another crucial aspect highlighted by the AAIDD is to refer to tools that "should provide robust standard scores across the three domains of adaptive behavior" (Schalock et al., 2010; p.49): the use of well-standardized instruments yields quite unbiased results. Moreover, being the adaptive behavior context-specific, it will be necessary to use tools that are standardized for the cultural/geographical group to which the individual belongs. In fact, in the evaluation of adaptive functioning, changes are usually made to the tools used to make them applicable in the different cultural contexts (e.g., some items of Receptive or Expressive Subscales in Italian version of Vineland II Survey Interview Form are modified with respect to American version).

Although only in the fifth edition of the DSM, the assessment of adaptive functioning has been included as a criterion for the definition of severity levels of ID, over 200 rating scales have been produced since the 1970s. However, in 2012, Tassé and colleagues established that only four standardized adaptive behavior instruments had characteristics and psychometric adequate properties to be used in the clinical determination of ID. These four instruments are: Adaptive Behavior Assessment System, second edition (ABAS-2; Harrison & Oakland, 2003); Adaptive Behavior Scale – School, second edition (ABS-S: 2; Lambert et al., 1993); Scales of Independent Behavior-Revised (SIB-R; Bruininks et al., 1996); and Vineland Adaptive Behavior Scale, second edition (VABS-2; Sparrow et al., 2005).

Over the years some tools have been updated; furthermore, new tools have been devised to assess adaptive functioning. To date, among the most popular and updated instruments on the international scene, it is possible to include:

- Adaptive Behavior Assessment System, third edition (ABAS-3, Harrison and Oakland, 2015).
- Vineland Adaptive Behavior Scale, third edition (Vineland-3, Sparrow et al., 2016).
- Diagnostic Adaptive Behavior Scale (DABS, Tassé et al., 2017).

The adaptive scales mentioned in these bullet points are better described below.

### Adaptive Behavior Assessment System or ABAS

Originally published by Harrison and Oakland (2000), this instrument has been revised with the publication of second (Harrison & Oakland, 2003) and third editions (Harrison & Oakland, 2015). Nevertheless, the third edition has not yet been adapted and standardized in all countries and for all age groups considered in the American version (from 0 to 89 years): for example, Italy adopts the second edition in children and adolescents from 1 to 18 years old (Italian edition Ferri et al., 2014). In the introduction of the latest American version of ABAS, the authors underlined that the ABAS-3 maintains "*all the essential features of ABAS-II and has numerous improvements*" (Harrison and Oakland, 2015; p. 1).

The *ABAS-3* consists of five distinct questionnaire forms:

- *Parent or Primary Caregiver Form 0–5 (from 0 years to 5 years and 11 months*): it examines the adaptive behavior of newborns, toddlers, and preschoolers at home and in other familiar contexts. Parents or caregivers who know the child can complete the ABAS-3 0–5 form.
- *Teacher or Day Care Provider Form 2–5 (from 2 years to 5 years and 11 months):* it assesses the adaptive behavior of toddlers and preschoolers in kindergarten or day care centers. The respondents are generally the teachers, support teachers, or other persons providing care for children.
- *Parent Form 5–21 (from 5 years to 21 years and 11 months):* it examines the adaptive behavior of children and young adults at home or in other familiar settings. Parents or other primary caregivers complete the ABAS 5–21 form.
- *Teacher Form 5–21 (from 5 years to 21 years and 11 months):* it is usually filled in by the teacher or teacher's aide and is used to assess children and young adults who still go to school.
- *Adult Form 16–89 (from 16 years to 89 years and 11 months):* it assesses the adaptive behavior of adolescents and adults at home or in other community settings. Parents or other people who know the examined person can fill it in. The person may also complete it himself/herself, but the scores must be interpreted with caution by the clinician, especially in the case of people with ID.

The respondent of the questionnaire evaluates if the assessed person is capable of a given adaptive behavior, and how often it can be observed through a Likert scale ("never," "sometimes", "almost always"). Furthermore, if the respondent doesn't have enough information about a specific adaptive behavior, he/she must note that his/her answer is only a supposition. Before delivering the questionnaire, the clinician needs to be sure that the respondent has understood all the instructions. It is important to point out that the respondent must answer taking into account the routine and not the potential performance of the exanimated person. Indeed, potential negative issues regarding parent completion of questionnaire include problems with comprehension of items and underestimation/overestimation (deliberate or unintentional) of the person evaluated.

The ABAS-3 investigates the adaptive skills areas, which may slightly differ in different forms (for more details see the User's Manual; Harrison and Oakland, 2015).

For example in *ABAS-3 5–21 Parent Form,* there are:

- *Communication:* the listening, comprehension, and linguistic production skills necessary to communicate with other people are investigated.
- *Community Use*: moving independently outside the home, making purchases, and calling technicians for home repairs are some of the abilities investigated.
- *Functional Academics*: basic pre-academic skills for reading, writing, and math or other skills like calculating the change after a purchase are investigated.

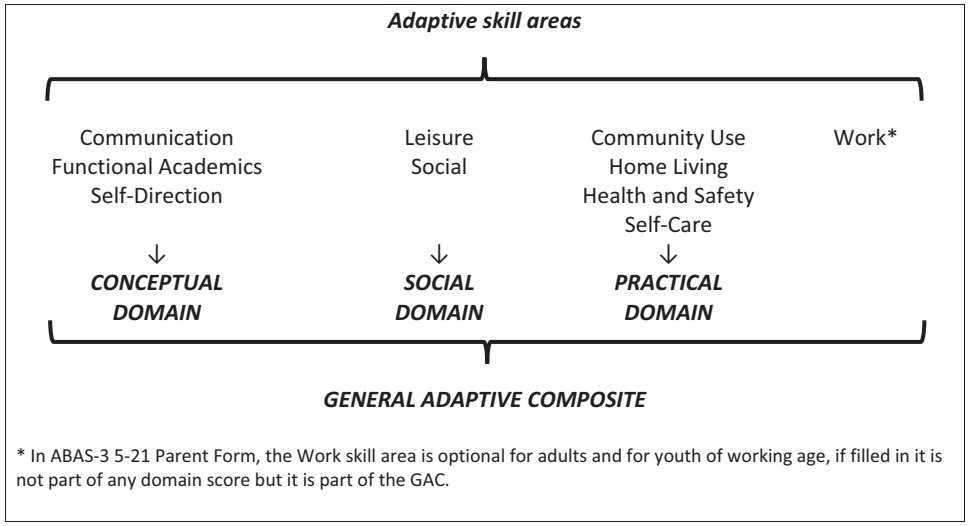


**Fig. 17.1** Example of adaptive skill areas, domains, and GAC in ABAS-3 5–21 Parent Form

- *Home Living:* skills needed for cleaning, tidying the house, preparing simple food, and using household appliances such as microwave are looked into.
- *Health and Safety*: this area evaluates the skills necessary for health protection such as following safety rules, keeping out of danger, and using medicines.
- *Leisure:* this area evaluates the skills needed to organize recreational activities or games and follow the games' rules.
- *Self-Care*: skills related to personal care like eating, dressing, bathing, and hygiene are investigated.
- *Self-Direction*: this area investigates the skills necessary for autonomy, responsibility, and self-control such as starting and finishing tasks, respecting time limits, and making choices.
- *Social*: this area investigates the skills necessary to socialize/maintain friendships. The person's abilities to express emotions and use good manners are also investigated.
- *Work*: the skills necessary for a good functioning and good management of both part-time and full-time work are investigated.

The results of each area are converted into scores with mean of 10 and standard deviation of 3. The ABAS-3 also generates three domains (Conceptual, Social, and Practical) and a General Adaptive Composite (GAC) (see Fig. 17.1). Both the domains and the GAC are expressed in standard scores (mean (M) = 100, standard deviation (SD) = ±15) and percentile rank. A qualitative description of the scores ("extremely low," "low," "below average," "average," "above average," "high") is also available to facilitate the interpretation of the results in both of the domains – including the GAC – and adaptive skill areas.

The standard scores of each domain and GAC help clinicians in making appropriate clinical decisions in ID according to DSM-5 criteria. No less important are the scores of the adaptive skill areas: they may provide further important implications for clinical practice to better plan intervention programs with specific goals.

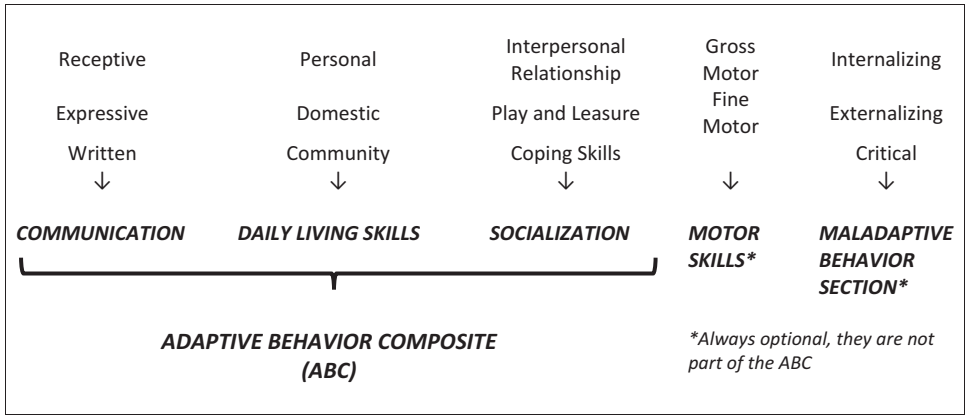


**Fig. 17.2** Example of adaptive domains, subdomains, and ABC in VABS-3 Interview Form or Parent/Caregiver Form

## The Vineland Adaptive Behavior Scales or VABS

The Vineland Adaptive Behavior Scales (VABS) represent the most used measure of adaptive behavior skills from birth to geriatric age. Since its first publication, the instrument allows to assess one person's development of independence and social responsibility, by using a semi-structured interview carried out with a person closed to the patient.

The Vineland Adaptive Behavior Scales have been recently released in its third edition (VABS-3) (Sparrow et al., 2016). The last edition consists of three forms:

- Interview Form: from 0 to 90+ years old.
- Parent/Caregiver Form: from 0 to 90+ years old.
- Teacher Form: from 3 to 21 years.

In the Interview Form, the interviewer does not read the items to the respondent, but uses open-ended questioning to help the caregiver to better describe specific behaviors. In the Parent/Caregiver Form and Teacher Form, the items are read and scored by the respondent who fills in the questionnaire.

As the previous edition, the investigated domains are: Communication, Daily Living Skills, Socialization, Motor Skills, and Maladaptive Behavior. However, in VABS-3, Motor Skills and Maladaptive Behavior are always optional. In fact, while Vineland Adaptive Behavior Scales 3 (VABS-2) included the Motor Skills domain in the computation of the Adaptive Behavior Composite (ABC) for children younger than 7 years, this is not true for any age on the VABS-3. This is one of the biggest changes of this new version which aligns with the adaptive domains (Communication, Social, Practical) encoded by DSM-5 (APA, 2013) and by AAIDD (Luckasson et al., 2002; Schalock et al., 2010, Schalock & Luckasson, 2021) (for a better definition, see section "History of Adaptive Behavior").

For each domain and ABC, raw scores are normalized in standard scores (M = 100, SD = ± 15) with lower scores indicating greater functional impairment.

Each domain is made up of subdomains which differ slightly depending on the Form (Interview or Parent/Caregiver versus Teacher) (see Fig. 17.2). Raw score of each subdomain is converted into normative data (M = 15, SD 3).

For example, Interview Form and Parent/Caregiver Form consist in:

- *Receptive subdomain*: it investigates how the individual listens and pays attention and what he/she understands.
- *Expressive subdomain*: it investigates how the individual uses words and phrases to provide information.
- *Written subdomain*: it investigates writing and reading skills from 3 years old.
- *Personal subdomain*: it explores how the individual eats, dresses, and takes care of personal hygiene.
- *Domestic subdomain*: it investigates how the individual takes care of the house from 3 years old.
- *Community subdomain*: it investigates how the individual orients him/herself, uses money and computer, and carries out work activities from 3 years old.
- *Interpersonal Relations subdomain:* it explores how the individual interacts with others.
- *Play and Leisure subdomain:* it investigates how the individual plays and manages free time.
- *Coping Skills subdomain:* it investigates how the individual manifests a sense of responsibility and care for others from 2 years old.
- *Gross-Motor subdomain*: it investigates how the individual uses arms and legs for movement and coordination.
- *Fine-Motor subdomain*: it explores how the individual uses hands and fingers when manipulating objects and drawing.

Each subdomain is composed of items that investigate the adaptive behaviors of the individual in a very detailed way. The clinician, in case of the Interview Form or the respondent, in case of Parent/Caregiver Form of Teacher Form, determines/evaluates if the assessed person is capable of a given adaptive behavior.

Assignment criteria are slightly different from the ones in VABS-2. In both versions, each item can be scored from 0 to 2; however, for example, in VABS-2, a score of 1 was assigned when a behavior was "sometimes" or "partially" observed, while in VABS-3, a score of 1 is assigned when behavior is observed "sometimes." A VABS-2 rating of "partially" allowed for the possibility that prompting of the behavior may have occurred; in the VABS-3, the behavior must occur spontaneously. Furthermore, there are also other more minor changes such as relocation of items between domains and updates to the language or the calculation of starting point (basal) or stop point (ceiling) (for more details see the User's Manual; Sparrow et al., 2016).

In conclusion, VABS-3 are the leading instrument for supporting the diagnosis of ID, specified by AAIDD and DSM-5. The tool can be used to take track of possible changes due to growth or intervention and to understand if a person needs specific support. In all their version, VABS represent the most used measure of adaptive functioning both in clinical practice and research, because of their high internal consistency, test-retest reliability, inter-interviewer reliability, and inter-raters reliability.

## Scales of Independent Behavior – Revised

As well as Vineland Scales, another test with an adequate standardization sample is the *Scales of Independent Behavior (SIB)* that has been introduced by Bruininks and colleagues (Bruininks et al., 1996).

In 2012, Tassé and his colleagues (2012) have revised the instrument, publishing the *Scales of Independent Behavior – Revised (SIB-R)* that represent one of the main standardized adaptive behavior instruments with characteristics and psychometric properties sufficient to be used in the clinical determination of intellectual disability. It contains norms for individuals from 3 months to over 80 years old and investigates cognitive abilities, social skills, physical disabilities, and needs of sup-

port. The SIB-R may be administered in a structured interview or by a checklist procedure in which the respondent completes the questionnaire. The SIB-R contains 14 subscales that fall into four main clusters: social interaction/communication skills, personal living skills, community living skills, and motor skills. It investigates the presence of eight areas of problem behavior, too. Scores range from 0 (never does) to 3 (does very well-almost always). SIB-R provides a Broad Independence Standard Score a 4 Domain Standard Scores (M = 100, SD = ±15).

### Diagnostic Adaptive Behavior Scale

The Diagnostic Adaptive Behavior Scale (DABS, Tassè et al., 2017) assesses adaptive behavior in people from 4 to 21 years old. It is a standardized test based on the tripartite model of adaptive behavior that includes conceptual, social, and practical domains (see section "Adaptive Behavior: Assessment"). Compared to other adaptive behavior scales, the DABS was specifically constructed to provide information around the decision point for identifying the presence or absence of significant impairment in adaptive behavior for the diagnosis of ID.

The DABS is a semi-structured interview that is conducted with a respondent who well knows the person assessed. The scale includes 500 items that are rated with a score range from 0 to 3: 0 = No-rarely or never does it; 1 = Yes-does it with reminders or assistance but rarely or never independently; 2 = Yes-does it sometimes independently – but sometimes needs reminders or assistance; 3 = Yes-does it always or almost always independently – never or rarely needs reminders. Also available as an exceptional rating is the "No Score." The "No Score" should be used only if the assessed person has a lack of opportunity due to cultural, gender, and/or geographic/regional factors, a lack of opportunity due to environmental constraints, or if the respondent has no direct knowledge of individual's typical performance.

The scale provides standard scores (M = 100, SD = ±15) for conceptual, social, and practical adaptive skills and an overall adaptive behavior score that measures the global adaptive functioning.

## Other Measurements for Assessing Adaptive Functioning as Part of Scales of Evaluation of Psychomotor Development

### Adaptive Behavior in the Denver Developmental Screening Test and the Denver II

The Denver Developmental Screening Test (DDST) (Frankenburg et al., 1967) is one of the most popular measures of developmental problems in young children. Since its first publication in 1967, it has been standardized in over 12 countries. In 1992, a revised version, named Denver II (DDST II), has been published and nowadays it is used in public health clinics, private practice, and clinical research (Frankenburg et al., 1992). Furthermore, the American Academy of Pediatrics Council on Children with Disabilities has Denver II on its approved screening tools list.

The DDST II consists of 125 tasks and is a quick screening in the examination of the pediatric patients to determine whether infants and preschool children are achieving developmental milestones. It can be administered to children from birth to 6 years of age. The scale is both an observational assessment and an assessment based on parental report. It is important to underline that DDST II is not a QI Test or a diagnostic tool. Furthermore, it does not allow to predict later development; then, if a child fails the DDST screening, a more formalized assessment (i.e., with the Bayley Scales of Infant Development; Bayley, 2006, 2019) is recommended.

DDST II provides an organized clinical impression in four main domains:

1. *Social and Emotional:* getting along with people, smiling at people, caring for personal and other people emotions, etc.
2. *Language/Communication:* hearing, understanding, using words, etc.
3. *Cognitive:* learning, thinking, problem-solving, etc.
4. *Movement/Physical Development:* sitting without support, putting block in cup for fine motor and jumping for gross motor, etc.

Scoring depends on age and ability of child and each item is scored as pass, fail, or refused.

Even though DDST II represents an overall evaluation of developmental delay, it can give information also about adaptive behavior in children. For instance, the Movement/Physical Development Domain may be used as an indicator of practical skills during daily life (i.e., in the "4 years range," the item "pours, cuts with supervision, and mashes own food" reminds the subscale "Home" in the VABS-2; see section "Vineland Adaptive Behavior Scales - VABS").

To conclude, even if not diagnostic by itself, this test is useful for detecting children (such as those with HIV, hypoxic-ischemic encephalopathy, or ID) who have global problems or who fail in a specific domain, extrapolating information also about adaptive functioning. The instrument can also be used to track childrens' development over time.

## Adaptive Behavior in Bayley-III and the Bayley-4

The Bayley Scales of Infant and Toddler Development (BSID) is an individually administered instrument originally developed by psychologist Nancy Bayley to assess the development of children aged 1–42 months (Bayley, 2006). Since its first publication, the scale has been revised different times and is nowadays on its fourth edition (Aylward, 2020). The third and the fourth edition are the most used versions during both clinical practice and research activity.

The *Bayley-III* (BSID-III) assesses infant and toddler development across five main domains: Cognitive, Language (Receptive and Expressive), Motor (Gross and Fine), Social-Emotional, and Adaptive. Assessment of the first three scales is conducted using items administered directly to the child. Assessment of the latter two scales relies on primary caregiver interview. Each subscale can be administered independently, then the instrument is very useful also in multidisciplinary evaluations. The instrument allows to identify children's strengths and weaknesses, to establish if a deeper assessment is required, and to take track of development changes and progresses of an eventual intervention.

The Bayley-III employs the Parent/Primary Caregiver Form of the ABAS-2 (Harrison & Oakland, 2003) as its Adaptive Behavior Scale. Thus, the items included on the Parent/Primary Caregiver Form of the ABAS-2 are the same as those included on the Adaptive Behavior Scale of the Bayley-III. The Bayley-III manual underlines that the scale is based on (1) the conceptualization of adaptive behavior promoted by AAIDD (see section "History of Adaptive Behavior") and (2) the legal and professional standards applicable to disability classifications, provided by the DSM IV-TR (APA, 2000).

*The Bayley-4* (BSID-4) has been introduced to conduct developmental assessments in order to identify children with developmental delay so that early intervention services could be provided. As the previous version, it contains five core domains (see above) that are administered to infants and toddlers from 16 days to 42 months of age. Compared to BSID-III, the new version includes questions for the caregiver. For instance, adaptive behaviors on the Bayley-4 are measured solely via caregiver report because self- or teacher-report obviously cannot be obtained for children in this age range. Moreover, BSID-4 takes approximately 30% less time to complete the assessment than the previous editions. In addition, while scoring on BSID-III is dichotomous (1, 0), in BSID scoring is polytomous

(2, 1, 0), where 1 means that the skill or behavior is emerging. Another main difference is that in BSID-4 *the adaptive behavior scale utilizes Vineland Behavior Assessment System* rather than ABAS-2 one. More specifically, the Bayley-4 Adaptive Behavior Scale consists of 120 items selected from the Vineland-3 (Sparrow et al., 2016).

It is interesting to notice that the three domains of the Bayley-4 Adaptive Behavior Scale, namely Communication, Daily Living Skills, and Socialization, are compatible with the adaptive behavior areas specified as necessary for the diagnosis of ID by the AAIDD (Schalock et al., 2010) and the DSM-5 (APA, 2013). In fact, the terms conceptual, practical, and social used by AAIDD and DSM-5 correspond to the domains of Communication, Daily Living Skills, and Socialization of the Vineland-3 (and the Bayley-4). Deficits in these areas reflect the impact that the adaptive skill deficit has on the individual's day-to-day function. On the Bayley-4, severity is reflected by standardized scores.

To conclude, the Bayley Scales is an useful tool to early identify ID, to assess the principle domains of development, such as adaptive behavior, and to investigate changes over the growth.

## When Standardized Scales Cannot Be Used

In some cases, adaptive behavior standardized assessments cannot be used, for example, when there are not reliable or closed people who can answer for the patient's adaptive functioning. In these situations, other information regarding adaptive functioning can be adopted:

1. *Direct observation*: What does the person really do? How does the person interact with other people? How much is the person able to take care of him/herself?
2. *External sources of information*: School records, medical information, previous cognitive, and psychological evaluations.
3. *Interviews* with closed respondents who are not able to complete a standardized assessment, but can give qualitatively important data.

When structured evaluations cannot be performed, the examiner should use multiple types and sources of information combined with clinical judgment. It is important to remember that adaptive behavior is different from problem behavior. More specifically, behaviors that interfere with one person's daily life (i.e., a child throwing objects to seek adults' attention) are defined as maladaptive behaviors and not as the absence of adaptive behavior (i.e., the same child could be able to more maturely interact with meaningful others, but could not exhibit this skill in certain situations). The clinician, when using direct observation, should be cautious in order not to overestimate or overlook individual's disability. To this purpose, clinical expertise and specific trainings are essential when working in the field of ID.

## Adaptive Behavior in Some Neurodevelopmental Disorders

### Adaptive Functioning in Individuals with Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a group of neurodevelopmental disorders characterized by deficits in social-communication skills and the presence of repetitive or restricted patterns of behaviors and/or interests. The estimate prevalence of ASD in the American population is 1:54 (Maenner et al., 2020). As the word "spectrum" suggests, individuals with ASD show a wide heterogeneity in core symptoms severity, in cognitive and language level as well as in adaptive functioning.

Researchers have shown that this heterogeneity is also reflected in clinical outcomes. Early diagnosis and early treatment based on ABA (such as Early Intensive Behavioral Intervention (EIBI),

Pivotal Response Training (PRT), or Naturalistic Developmental Behavioral Intervention (NDBI) such as Early Start Denver Model (ESDM), Cooperative Parent Mediated Therapy (C-PMT); Lovaas and Smith, 2003; Koegel et al., 1999; Dawson et al., 2010, Valeri et al., 2020) has increased the percentage of individuals with ASD with a good level of functional and adaptive independence in adulthood. However, there is still a great number of individuals with ASD (at least a half) who fail to reach good outcomes in terms of independence showing vulnerabilities during their entire life (Billstedt et al., 2005; Eaves & Ho, 2008; Howlin et al., 2004; Tsatsanis, 2005).

It is well-known that IQ and language level are consistently correlated to positive outcomes in ASD (Billstedt et al., 2005; Howlin et al., 2004). However, the role of adaptive functioning is less clear. Findings from a longitudinal study that lasted 20 years have shown that the correlation between IQ and adult success in individual without cognitive impairment is weaker than thought. On the contrary, these authors found that the adaptive skills are more associated with good outcomes compared to IQ and language level in this portion of population. In fact, some individuals with ASD could have a high IQ, but limited adaptive skills, while others with borderline cognitive and good level of independent life-skills could reach good outcome rating.

However, the role of adaptive level in predicting adult outcomes has been still not fully explored. In a relatively recent review, Magiati and her colleagues (2014) examined the relation between several variables measured in childhood and adult outcomes of individuals with ASD. None of the 25 studies included in this review has examined the presence of relationships between adaptive level in childhood and adult outcomes. These results showed a tremendous lack of research on the relation between adaptive functioning and adult outcomes, thus showing a great importance to further explore this relation in future research. Nonetheless, we are aware of the important role of IQ and language level in predicting adult outcomes; a better knowledge of the role of adaptive functioning will allow researchers to predict the role of patterns of IQ, language level, and adaptive functioning more precisely.

For example, having a good level of daily living adaptive skills in childhood could be crucial for a child with ASD and severe cognitive impairment. Those skills could be related to his functional independence in adulthood, to parental burden (by easing parents in daily assistance), and therefore to personal and familiar quality of life. Furthermore, those abilities could contribute to other related abilities such as those involved in a job. Being able to organize daily routine in childhood could be related to the ability to organize work routines and demands in adulthood. On the contrary, the same adaptive daily living skills could be less important for a child with ASD without cognitive impairment where higher-level abilities are expected. Other skills, such as "fine-grained" communication and socialization skills, could play a major role in reaching a satisfactory life for adult people without cognitive impairment when compared to people with cognitive impairment.

The future exploration of the role of adaptive functioning in predicting adult outcomes could bring to a better definition of intervention plan in childhood, thus improving the quality of life of individual with ASD and their families. However, this kind of information is actually limited.

In the following sections, we will shortly review adaptive profile of individuals with ASD in cross-section and longitudinal studies and his predictors. The review of literature is not intended to be exhausting, given the limited space. We will just describe main studies to depict a picture of autism adaptive profile.

## Adaptive Profile of Individuals with ASD

The greatest part of the studies on adaptive functioning in ASD has been conducted with Vineland Scales (i.e., Paul et al., 2004; Tomanik et al., 2007). Most studies have shown that people on the spectrum show deficits in adaptive functioning independent from cognitive level. These studies agree to define a typical "autism profile" characterized by a marked impairment in socialization, weakened

delay in adaptive communication, and a relative strength in daily living skills (Bolte & Poustka, 2002; Carter et al., 1998). However, all the scores are usually under the average.

Some authors have found that the impairment in adaptive functioning may vary according to the level of cognitive ability. An adaptive level below the average has been found in individuals with ASD with higher functioning (i.e., Perry et al., 2009; Saulnier & Klin, 2007), while individuals with lower functioning and cognitive impairment showed an adaptive behavior on par with cognitive level or, sometimes, above (i.e., Perry et al., 2009). Furthermore, the gap between IQ and adaptive skills in individuals with higher functioning could be enlarged with the growth; some studies have shown that this discrepancy between IQ and adaptive level increases with the age (Szatmari et al., 2003).

Concerning change in adaptive functioning over the time, the heterogeneity of ASD has complicated the possibility to depict trajectories of adaptive functioning. While a static picture of autism profile has been defined over the time in several studies, there is still dearth of longitudinal studies on adaptive functioning in ASD. However, two major studies provide important information that help to predict the adaptive functioning over the time.

A relatively recent study from Szatmari and his colleagues (2015) has allowed to partially fill this gap in knowledge. In a large sample (416 children with autism) followed from approximately 3–6 years old, they found three different groups based on baseline Adaptive Composite Score on VABS-2 and the trajectory over the time: Group 1 with lower functioning and worsening trajectory (around 30% of the sample), Group 2 with moderate functioning and stable trajectory (around 50%), and Group 3 with higher functioning and improving trajectory (around 20%). However, these results are limited to a global measure of adaptive level (Adaptive Composite Score) and do not provide any information on specific scales (Communication, Socialization, and Daily-living skills). Furthermore, this study is limited to a preschool sample, while the trajectory of adaptive behaviors could further modify over the years.

A wider and deeper investigation comes from Baghdadli and her colleagues (2018), who followed a group of 106 individuals with ASD for 15 years approximately from 4 years to 20. Considering results as a whole, the authors found that adaptive functioning was below the average all over the time. However, they found that adaptive functioning showed significant improvement over the time in socialization, communication, and daily-living skills in approximately 20% of the population, confirming results from Szatmari's study. Interestingly, improvement in this portion of population was significant as predicted by lower autism symptoms and higher language/intellectual levels at time of inclusion. Surprisingly, adaptive level at baseline did not predict adaptive level in the last timepoint, thus making hard a prediction of the trajectory based on the first adaptive assessment. However, the results from this study must be considered carefully, given that 80% of the population included had a coexistent intellectual disability.

Taken together, the research here shortly summarized the need to focus on adaptive functioning in all the spectrum independently from age, cognitive level, and autism symptoms. The most consistent finding is that all people on the spectrum experience some trouble in keeping pace with typical social/cultural standards of personal independence. This is well-known by families of individuals with ASD. Research suggests that adaptive functioning (in particular daily living skills) is a significant predictor of family quality of life (Gardiner & Iarocci, 2018) in adolescence. This stage of life is crucial in individuals with ASD. While a great number of services and intervention are now available for children with ASD, services for adolescents and adults are somehow limited and/or available only for people with high socioeconomic level. Furthermore, while some social routines (such as group participation) could be mediated by the presence of a caregiver (teacher, therapist, parent) during childhood, adult-mediation, it is not socially accepted during adolescence and adulthood. These factors could further increase the gap on reaching independence between individual on the spectrum and individuals with typical development.

Summing up, there are a large number of studies that cast light on the critical role of adaptive functioning. Focusing on adaptive functioning during treatment in earlier stage of treatment would help to increase all abilities that could be important for the people we are working on. However, given that intervention resources could be limited, it is important to choose adaptive skills that could be relevant for that specific person in order to live as much as independent in his social group.

### Factors That Could Affect Adaptive Behavior in ASD

The knowledge of factors that could affect adaptive behavior in ASD could help in designing effective intervention plan to improve adaptive level of individuals with ASD.

The most consistent predictors of a good adaptive functioning are cognitive and language level (Szatmari et al., 2015), while the role of ASD symptoms is less clear with studies finding mixed results (Perry et al., 2009). Despite their importance, IQ and language level seems to have small effects on adaptive functioning in individuals without ID, while other research suggests that executive functioning could have greater effects (Pugliese et al., 2015). Recent studies (12 years follow-up) showed that executive functioning when assessed in preschoolers could predict adaptive level in Communication, Daily Living Skills, and Socialization skills (Pugliese et al., 2015). Deficit in executive functioning, such as ability to self-monitoring, problems in inhibition or shifting, are frequently reported in people on the spectrum (Christ et al., 2007; Hill, 2004; Luna et al., 2007; Kenworthy et al., 2008). Self-monitoring refers to the skills to monitor one's own behavior to reach a predefined goal and modify one's behavior accordingly. Deficit in this area has been related to some ASD symptoms such as repetitive behaviors, perseverative responding, and joint attention deficit (Hill, 2004). Inhibition is the ability to suppress an automatic response voluntarily and deliberately. Difficulty in inhibition is often connected with some deficit in ASD such as ability to turn-taking during conversations with others. "Shifting" is the skill to intentionally move thoughts and actions in response to changes in environment. Also, this ability has been linked with some deficits in individuals with ASD (Granader et al., 2014; Rosenthal et al., 2013) such as lack of flexible thinking, difficult to cope with new social situations, or difficulty with change in environment resulting in "meltdowns." These abilities may significantly impact relationships of individuals with ASD throughout the lifespan. Focusing intervention on these abilities could lead to higher adaptive level, especially in individuals without ID.

Interestingly, an ultimate factor that could affect the adaptive functioning is the presence of siblings in the family. Individuals with siblings experienced increasing adaptive growth trajectories in longitudinal studies when compared to individuals without siblings (Rosen et al., 2021). The result from this study emphasizes the role of siblings in increasing adaptive skill in most individuals consistently with literature describing positive effect of siblings on development (see work on theory of mind, social communication, and nonverbal communication (i.e., Matthews & Goldberg, 2018; Ben-Itzchak et al., 2019)).

## Adaptive Functioning in Individuals with Williams-Beuren Syndrome

Williams-Beuren Syndrome (WBS) is a rare disorder (1:7500) related to a de novo hemizygous microdeletion on chromosome 7q11.23. The deletion usually ranges from 1.55 Mb in 95% of cases to 1.84 Mb in 5% of cases (Osborne et al., 2001; Bayés et al., 2003; Schubert, 2009). A common feature in most of the individuals with WBS is the presence of hyper-sociability. A global developmental delay, with relative spared language skills and deficit in visuospatial skills, is usually found (Alfieri et al., 2017; Vivanti et al., 2018).

Despite less renowned, also individuals with WBS share several problems in reaching an independent life. By following Elison and her colleagues (Stinton et al., 2010) in one of the widest studies on

outcomes, only 8% of 92 adults with WBS included in the study lived completely independently. The remaining participants were living in residential accommodation for people with intellectual disabilities (39%) or with their parents (53%). Furthermore, only 7% of participants had a regular employment with a regular payment, while the remainder were employed in "special job," in voluntary unpaid job, or unemployed. Interestingly, despite their hyper-sociability, about a third of the individuals included in the study have poor abilities to create and maintain friendship relationships and a half of them were described as having a poor comprehension of the concept of friendship.

Similarly to what happens in ASD, also in WBS IQ is one of the major predictors of good outcomes in independent life, particularly concerning self-care, social impairment, and occupational functioning. Individuals with higher IQ tend to reach higher satisfaction in described areas. Furthermore, this study has also found that Vineland Adaptive Behavior Composite (ABC) plays a major role in self-care, social impairment, and occupational functioning, as well as in behavioral impairment and physical health problems.

Taken together, these data highlight the difficulties of individuals with WBS in reaching a satisfying independent life. However, research on this topic is still scarce and further investigation would help describing adaptive profile associated to good outcome in this syndrome.

In the next sections, we will review the research on adaptive profile of individuals with WBS in cross-section and longitudinal studies, which are the predictors of adaptive level. Again, we will just describe main studies to depict a picture of WBS adaptive profile, without any intention to be fully exhaustive.

### Adaptive Profile in Individuals with WBS

In a recent review, most of the individuals with WBS shared a global adaptive profile below the normal range both in preschoolers and in schoolers, with a wide range of functioning for all ages considered in this study. While some individuals showed functioning profoundly or severely impaired, others have an adequate or moderately low adaptive level (Hahn et al., 2014; Howlin et al., 2010; Mervis & John, 2010; Mervis et al., 2001).

The analysis of adaptive profile in preschoolers with WBS has shown mixed results. Differently from what happens in ASD, pattern of strengths and weaknesses differs from one study to another and tends to modify over the years. These differences could be due in part to the different assessments used in investigation, and in part to modification in adaptation to evolutionary tasks.

The main studies on adaptive functioning in preschoolers have used both old and new version of Vineland as well as ABAS-2. While some authors (Kirchner et al., 2016) did not find any relevant differences between scales in adaptive levels (16 preschoolers, with mean age of 28.7 months) by means of ABAS-2, others found uneven pattern of strengths and weaknesses. For example, Hahn and her colleagues (2014) have highlighted a profile characterized by strengths in communication and socialization (18 prescholeers, with mean age of 47 months), using Vineland Adaptive Behavior Scales – Interview Edition, Survey Form. Furthermore, other authors (Hamner et al., 2019) showed a relative point of strength in socialization (but not communication) by means of the parent report form of VABS-2, in a sample of 18 children with mean age of 47 months, while others (Alfieri et al., 2021b) found only strength in communication (but not in socialization) by means of the Vineland Adaptive Behavior Scales – Interview Edition, Survey Form. Beyond heterogeneity of tools used, the main limitation of these studies is the limited sample presumably due to the rareness of the disorder.

However, the results of the studies become more consistent by moving from preschoolers to scholars. Most of the research show that socialization and communication domains are usually found above other domains (Mervis et al., 2001; Mervis & Klein-Tasman, 2000). Interestingly, all the studies in scholars' sample have used the same tool (Vineland Adaptive Behavior Scales – Interview Edition, Survey Form), accounting for the unevenness of results in research on early stage of life. Moving to

studies on adulthood, a different profile emerged, with socialization that remained a strength, while Daily Living Skills and Communication fall in the lowest areas of functioning (Cherniske et al., 2004; Howlin et al., 2010).

As per ASD, longitudinal studies on adaptive functioning are limited also in WBS. As far as we know, only three longitudinal studies have been conducted. Fisch et al. (2010) found a relative stability in functioning after 2 years in children and adolescents. Differently, Mervis and Pitts (2015) found a significant decrease of adaptive functioning after 3 years follow-up (in particular, in Motor Skills and Community Living skills, while Communication and Socialization were more stable). Howlin and colleagues (2010) found a significant improvement in Socialization and Daily Living adaptive skills in the longer study available (12-year follow-up), suggesting that some adaptive skills could improve over time. Concerning group trajectories, Mervis and Pitts (2015) found that many children (around 42%) showed a significant decline, while only a smaller proportion (7%) of their participants had a significant improvement.

One of the most known characteristics of individuals with WBS is the hyper-sociability and the interest in people. For that reason, WBS has been considered a disorder on the "polar opposite" of autism for a long time (Schultz et al., 2001). However, recent investigation has revealed that WSB and ASD show more similarities than differences (Alfieri et al., 2022). In fact, children with ASD and those with WBS show some kind of deficit in socio-communicative abilities: problems in shared attention, showing or giving objects in preschool age; troubles in social relationships, pragmatic language, and emotional awareness in school age (Vivanti et al., 2018). Furthermore, despite relative preserved language abilities, only expressive skills in adaptive profile were higher mental age, while receptive skills were found significantly lower, thus indicating difficulties in comprehension including pragmatic skills (Alfieri et al., 2017).

For that reason, cross syndrome studies have been conducted in order to assess similarities and differences between adaptive profile of individuals with ASD and WBS (Hamner et al., 2019, Alfieri et al., 2021a; Alfieri et al., 2022). Interestingly, results from these studies showed that, when matched for age and cognitive level, individuals with ASD and WBS were globally similar on adaptive level. Some differences emerge only in preschoolers in communication (Alfieri et al., 2021b) and socialization (Hamner et al., 2019), but these differences were not found in scholars. These results further emphasize the difficulties in social-communicational skills of individuals with WBS. While the hypersociable personality should persuade that individuals with WBS would have poor problem with socialization, this characteristic seems to have a good impact on their social relationships only in early stages of life. However, when friendship and other relationships become more complex and demanding, difficulties emerge also in this population so much that no significant difference between individuals with ASD and WBS emerges in this research (Alfieri et al., 2021a). This is confirmed from data on outcomes of adult individuals with WBS where around 30% fail to have stable relationship with other people. Interestingly, a similar proportion of individuals with WBS show social-communication problems during childhood (Klein-Tasman et al., 2007, 2009, 2018) in structured assessment conducted with gold standard tools for autism diagnosis.

### Factors That Could Affect Adaptive Behavior in WBS

The most consistent predictor of adaptive behavior in individuals with WBS is IQ (Mervis et al., 2001; Alfieri et al., 2021a). However, also other features have been considered for their relationship with adaptive functioning WBS such as the ability to request help when completing tasks and low persistence in completing tasks for preschoolers. Considering "hot executive functioning," Phillips (2008) reported that difficulties in emotion regulation are related to lower adaptive functioning in preschoolers (especially in Motor Skills and Personal Living Skills) beyond and above intellectual level. Finally,

other useful information is derived from Mervis & John, (2010), who showed that difficulties in sensory regulation are related to poorer adaptive functioning both in children and adolescents.

## Adaptive Functioning in Individuals with Fragile X Syndrome

Fragile X Syndrome (FXS) is a genetic disease inherited through X chromosome, included since 2001 among Rare Genetic Syndromes as it occurs in only 1/4000 males and 1/8000 females (Salcedo-Arellano et al., 2019). It was first described in 1943 by Martin and Bell, from which the condition takes its second name (it is also called "Martin-Bell Syndrome"). However, the molecular basis of FXS was discovered only in 1991, when the FMR1 gene (Fragile X Mental Retardation 1) located on the long arm of the X chromosome and whose mutation gives rise to the Syndrome, was isolated for the first time (Corona & De Giuseppe, 2018).

FXS is actually considered the most common inherited cause of ID, the second most prevalent cause after Down syndrome, and the most common monogenic cause of ASD.

The condition is caused by an abnormal expansion in the number of trinucleotide CGG (cytosine-guanine-guanine) located in the 5' UTR in *FMR1* at Xq27.3. More specifically, it is the result of the expansion of the CGG repeat in each generation moving from the permutation range of 55–200 repeats and expanding to a full mutation when passed by a mother to her children (Nolin et al., 2003). FXS patients have more than 200 repeats of this codon. Interestingly, people with permutation (55–200 repeats), although not affected by XFS phenotype, may exhibit other medical, psychiatric, and cognitive symptoms that can interfere with their daily life but also with their children's adaptive functioning (Moser et al., 2021). Very common medical problems in premutated people are Fragile X Associated Tremor/Ataxia Syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI).

*FMR1* gene encodes the Fragile X Mental Retardation Protein (FMRP), which binds several mRNAs, mainly in the brain and testicles, which are the most affected areas. Indeed, people with FXS exhibit language delay, hyperactivity, anxiety and mood disorders, cognitive deficits, learning disabilities, and macroorchidism in males. Girls are usually less affected than boys and only 25% of FXS women have ID.

Much of what has been published about the link between the genotype of people with FXS and the degree of neurobehavioral functioning is based on the measure of the CGG trinucleotide levels and the consequent quantity of FMRP produced (Garber et al., 2008). However, adaptive behavior is one of the most reliable indicators for assessing outcome in children with developmental disorders, such as Fragile X Syndrome, because it represents a more significant estimation of real-life skills.

In the following paragraphs, we will shortly review adaptive profile of people with FXS in longitudinal and cross-section studies. Factors that may influence adaptive behavior in FXS will be analyzed too.

### Adaptive Profile in Individuals with FXS

Research on adaptive behavior, overall and within behavior domains (i.e., communication, socialization, daily living, and motor skills), has identified three main possible development trajectories in people with FXS: (1) declines over time (i.e., Klaiman et al., 2014), (2) normal development until the age of 10 and then decline or stabilization (i.e., Fisch et al., 1999), and (3) steady increase from early childhood until adolescence (i.e., Hatton et al., 2003). Those different outcomes may be influenced by the different ages of people included in the various research samples, types of standardized scales and scores used (i.e., standard vs. raw scores), and by the presence/absence of comorbidities in the FXS individuals who have been studied.

However, results from the most recent longitudinal studies (i.e., Hahn et al., 2015) agree that middle childhood is a critical age period for adaptive behavior in FXS. A considerable number of children with FXS lose the adaptive behavioral skills previously learned both in relation to their peers and in absolute terms. The biggest decline can be observed in the socialization and communications domains, in line with the pragmatic, receptive, and expressive language difficulties observed in people with FXS (Abbeduto et al., 2016).

In contrast, daily living abilities (i.e., housekeeping, using public transportation, using community services, using mobile-phones, etc.) seem to be a relative strength also with growth (Hatton et al., 2003).

### Factors That Could Affect Adaptive Behavior in FXS

The first research on behavioral functioning in FXS focused on the correlation between FMRP expression and phenotypes outcomes. For instance, Cohen et al. (1996) in a study comparing people with full mutation versus *FMR1* mosaicism showed that individuals with complete FXS had lower adaptive functioning, a result that was interpreted to be due to the amount of FMRP produced. However, biological factors cannot explain alone the adaptive behavior patterns observed in people with FXS. Then, other contributors to adaptive behavior should be taken into account, such as cognitive abilities. Several studies showed that IQ scores tend to decline over the time and a positive correlation between performance on intelligence tests and adaptive behavior scores has been observed, especially in women (Glaser et al., 2003). The biggest interrelationship has been underlined between IQ scores and the Adaptive Behavior Composite measured with VABS.

Furthermore, in confirmation of the importance of context factors explained in section "Adaptive Behavior: Assessment", it has been observed how home environment is one of the most significant predictors for long-term adaptive functioning. Parental expectations, parenting skills, home facilities, and emotional climate influence adaptive functioning more than anything else. Then, the finding of a positive correlation between lack of adaptive skills in FXS children and severity of premutation in their mothers is not surprising (Mooser et al., 2021).

In addition to cognitive abilities, the co-occurrent presence of ASD influences adaptive functioning. For instance, Smith and colleagues (2012) in a cross-syndromes study showed that individuals dually diagnosed with FXS and ASD displayed a more severe impairment in social and communication domains than people with FXS only.

Summing up, people with FXS exhibit adaptive behavior deficits that can be due to biological factors, IQ level, comorbidity with other diseases, and environmental factors. Home environment is the most significant predictor of adaptive behavior in people with FXS.

## Conclusion

Adaptive behavior refers to the skills requested to function in everyday life and to cope with different life demands. It comprehends social interaction, communication, practical, and motor skills, which are all important to living a life worth living.

The current definition of ID includes deficits in both intellectual and adaptive functioning with degree of disability assigned according to adaptive behavior impairment. For this reason, adaptive behaviors should be always evaluated during ID assessment. Standardized and reliable tools should always be used. Identifying weaknesses and strengths in one person's adaptive functioning is essential to better understanding specific disorders and for the development of novel interventions. In fact, it has been observed that in different neurodevelopmental disorders, there is a regression in adaptive

behavior skills that inevitably interferes with the possibility to gain independence in adulthood. This acknowledgment rises an important question: is the decline in adaptive behavior possible to prevent?

Researchers and clinicians have the important responsibility to answer this question and implement new and early intervention strategies.

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