Adulthood Begins in Preschool: Meaningful Curriculum in Support of Increased Independence for Individuals with Autism

Peter F. Gerhardt[a,*], Shanna Bahry[b,] Natalie M. Driscoll[c], Jessica Cauchi[d], Brian K. Mason[e], Madhura Deshpande[f]

[a,*] **Corresponding Author:** Peter F. Gerhardt, Endicott College, Beverly, MA, The EPIC School, Paramus, NJ, USA.
E-mail: pgerhardt@epicschool.org
ORCID: https://orcid.org/0000-0003-1234-1753

[b] Shanna Bahry, Endicott College, Beverly, MA, Meaningful HOPE, East Providence, RI, USA.
E-mail: sbahry@endicott.edu
ORCID: https://orcid.org/0000-0002-4347-018X

[c] Natalie M. Driscoll, Endicott College, Beverly, MA, Seven Hills Foundation, Worcester, MA, USA.
E-mail: Ndriscol@endicott.edu
ORCID: https://orcid.org/0000-0003-3261-0172

[d] Jessica Cauchi, Endicott College, Beverly, MA, USA.
Atlas Behaviour Consultation, Oakville, ON, Canada.
E-mail: Jcauchi@endicott.edu
ORCID: https://orcid.org/0000-0001-6084-1846

[e] Brian K. Mason, Endicott College, Beverly, MA, USA.
Hamilton-Wentworth District School Board, Hamilton, ON, Canada.
E-mail: Bmason@endicott.edu
ORCID: https://orcid.org/0009-0000-4110-6133

[f] Madhura Deshpande, Endicott College, Beverly, MA, USA.
Momentum Learning Services, Sydney, NSW, Australia.
E-mail: Mdeshpande@mail.endicott.edu
ORCID: https://orcid.org/0009-0001-7163-4401

Abstract

A meaningful curriculum is one that is individualized, inclusive of the individual's unique needs and interests, and focused on building independence in current and future environments. A meaningful curriculum addresses an individual's needs and prioritizes instructional programs based on what is, potentially, most important to their lives and not simply a somewhat arbitrary list of isolated skills. A meaningful curriculum is one that puts as much emphasis on skill acquisition outside of the classroom as it does on skill acquisition within the classroom or school. Unfortunately, the use of meaningful curricula to educate autistic students would seem to be something of a rarity, which may help to explain the consistently poor outcomes that individuals with autism and related disorders experience in adulthood. In this article, the authors make recommendations that may help practitioners to mitigate these outcomes by providing instruction in curricula that place a focus on adaptive behavior skills, the intersection of the individual, respectful intervention, and an emphasis on these important topics beginning in preschool, and increasing in importance and complexity across the lifespan.

Introduction

Overall, individuals with an autism spectrum disorder (ASD) have poor adult outcomes when compared to same-aged peers in every area typically evaluated including employment, living arrangements, social and community participation, access to services, physical and/or mental health, and safety (Roux et al., 2015). Such outcomes have shown little improvement over time (Newman et al., 2010) and are worse than those of adults with other disability labels or identities (e.g., intellectual disability [ID], learning disability [LD], speech-language impairment, and emotional disturbance; Roux et al., 2015). On an annual basis, approximately 70,000+ autistic teens in the United States become adults (Autism Speaks, n.d.) but lack the necessary skills to successfully transition to an independent life after high school (Gerhardt & Lainer, 2011). On a macro-level, poor outcomes result in higher financial

costs to the family and to society at large (Dell'Armo & Tasse, 2018; Farley et al., 2018; Howlin & Magiati, 2017).

Upon leaving high school, autistic youth experience a drop in available services and supports that is generally referred to as a service cliff (Roux et al., 2015). While federal law (i.e., Individuals with Disabilities Act; IDEA, 2004) mandates the provision of special education inclusive of a plan to transition from school to the world of adult services, there is no similar obligation post-high school; this leaves families to fend for themselves when seeking appropriate services (Roux et al., 2015; Shattuck et al., 2020). Sadly, there is a backlog of service needs that easily exceeds the resources currently available (Gerhardt & Lainer, 2011). Over the next decade, Autism Speaks (n.d.) estimates that an additional 707,000-1,116,000 teens in the US will enter the world of adulthood, only further exacerbating this problem.

To address this problem, the role that parents, teachers, aides, behavior analysts, and related service providers need to play becomes nothing short of critical leading up to, and during, the transition to adulthood. While every student's transition plan should be individualized, every plan should provide attention to three major outcomes including employment, independent living, and happiness (e.g., Ticani & Bondy, 2014). Unfortunately, it seems that a combination of poor preparation leading up to adulthood and limited access to effective, individualized adult services, hinders progression toward such positive outcomes (Shattuck et al., 2020; Snell-Rood et al., 2020). Despite the fact that individuals on the spectrum can, and often do, make valuable contributions to the communities in which they live, they are often denied access to this opportunity. Providing a meaningful curriculum is one way to reduce such barriers and increase meaningful access.

What Makes a Curriculum Meaningful?

A meaningful curriculum is one that is individualized, inclusive of the individual's unique needs and interests, and focused on building independence in current and future environments (Ayres et al., 2011). A meaningful curriculum addresses an individual's needs and prioritizes instructional programs based on what is, potentially, most important to their lives. As positive adult outcomes can be predicted, in part, based on the adaptive behavior repertoire of an individual (Ayres et al., 2011; Dell'Armo & Tassé, 2018; Mazefsky et al., 2008; Mazzotti et al., 2016), instruction in adaptive skills lies at the core of any meaningful curriculum. Adaptive behavior is, essentially, any and all skills and abilities that allow independent functioning in their day-to-day life in the environment in which they live (Heward, 2005).

Adaptive skills are "so central to adult life that it would not be an understatement to say that good adaptive behavior skills will get a person through times of no academic skills better than good academic skills will get a person through times of no adaptive behavior" (Gerhardt et al., 2013, p. 167). Adaptive behavior should therefore be a priority in programming starting at a young age and increase in focus as individuals get closer to adulthood.

What is meaningful for some will not be meaningful for all and, as such, practitioners need to take the unique needs of each individual into consideration when confronted with general education standards. Strict adherence to the general education standards requires practitioners to target goals that will likely have little to no relevance to the adult lives of individuals. For example, learning to identify Saturn when you have not yet learned to brush your teeth would probably not be considered a meaningful goal for many (Ayres et al., 2011). There is a balance to goal development, and while academic skills may be part of a meaningful curriculum for some individuals, others may need to focus more on adaptive behavior competencies instead (although even the more "academic" student still needs to acquire meaningful adaptive behavior skills). In addition to academic skills and skills specific to the autism spectrum disorder (ASD) diagnostic criteria, other important adaptive skill domains include but are not limited to, self-care/hygiene, dressing, health maintenance, safety, cleaning/care of the home, cleaning/care of clothing, social skills and niceties, mealtime skills, community engagement, self-management, and leisure/recreation. A truly individualized and meaningful curriculum fulfills each individual's right to an appropriate education (Ayres et al., 2011; Ayres et al., 2012; Bahry et al., 2022b).

A meaningful curriculum should promote a balance between teaching high-value (high preference/high relevance) and low-value (low preference/high relevance) skills. A skill that is highly valued is more likely to be maintained over time, so should be prioritized in a meaningful curriculum (Gerhardt et al., 2013). However, low-value skills might also be important if they promote engagement, safety, or enjoyment in an indirect way. For example, showering may be a low-value skill to an individual, but mastery of the skill may lead to decreased body odor and increased neat appearance which may help promote engagement in social situations or the ability to get and retain a job (which both may be of high value). At the end of the day, applied skills are simply useful skills. If the skill is not valued, it will not be used; if the skill is not used often enough, the individual will likely, over time, lose their ability to display the skill.

A meaningful curriculum can be conceptualized as an antecedent-based behavioral intervention. When

caregivers and practitioners proactively set goals for young individuals with autism and other related disorders that are meaningful, the future risk of severe challenging behavior, abuse, and harm is reduced (e.g., Ala'i-Rosales 2019). Gaps in adaptive skills can be identified and targeted within the context of a meaningful curriculum, which can help to lower dependency on others across the lifespan and thus help to mitigate the risks discussed (Saulnier & Klaiman, 2022).

Meaningful Intervention and Challenging Behavior

A high prevalence of challenging behavior exists within the ASD population, specifically with such dangerous behavior as self-injury and aggression (e.g., Davies & Oliver, 2016). Often these behaviors develop as a result of skill deficits in other areas, such as communication. In a large population-based sample in the United States, self-injurious behavior (SIB) was reported to occur in more than 30% of children with ASD (Soke et al., 2016). Another large sample study found aggression to be reported in approximately 1 in 4 individuals with ASD, with a significant association found between aggression and overall cognitive level (i.e., IQ; Hill et al., 2014). The display of challenging behavior can, and often does, restrict the activity of adolescents and adults on the spectrum. Community-based instruction (CBI) often gets put on hold, as do job training opportunities due to the presence of challenging behavior. As such, a meaningful curriculum needs to adequately address these challenges to allow for increased skill acquisition in other important areas.

Despite having over 60 years of behavior analytic research focusing on the assessment and intervention of challenging behavior (Ala'i-Rosales et al., 2019), the vast majority of this research has been conducted in well-controlled research environments or clinics and not in a more typical environment (e.g., the classroom or the community). The complexity of autism education beyond the controlled environment (i.e., the real world) does not easily lend itself to well-controlled study conditions. Within the context of a meaningful curriculum, intervention with challenging behavior requires:

1. *Reductions in aggression or self-injury that result in positive changes to the individual's life*

   Reductions in the frequency of a particular behavior that does not result in increased community access or employment training opportunities for adolescents or young adults represents only part of the desired outcome.

2. *The development of a set skills that enables the individual to manage their own behavior and control relevant aspects of their environment*

   This could include, antecedent strategies such as behavioral relaxation/self-calming, functional communication training and support, context-appropriate refusal skills, the ability to accept delayed reinforcement, curricular modifications congruent with the individual's preferences, and environmental modifications that support greater access to positive reinforcement.

3. *A data-based justification that the behavior in question has a negative impact on the individual's quality of life or wellbeing*

   All of us engage in stereotypic behavior. The difference lies in our ability to recognize the social contingencies relevant to stereotypy and differentiate between "time in" conditions (when we can engage in stereotypy) and "time out" conditions (when we cannot engage in stereotypy). Any intervention targeting stereotypy needs to focus on teaching the individual how to recognize and respond to the two conditions.

4. *Recognition of each individual's right to be angry, irritated, or annoyed*

   This is only a problem when anger, irritation, or annoyance result in aggression or self-injury. Being pissed off is not a challenging behavior.

Intersection of the Individual

As previously discussed, a central feature of a meaningful goal is that it presents as meaningful to the student in question. In other words, meaningful goals require a much greater degree of individualization than do non-meaningful goals. Individualization of goals requires an ongoing evaluation of the intersection of the person and the environment, considering such parameters as personal preferences, dislikes, interests, and idiosyncrasies. When providing instruction either inside or outside of the classroom an understanding of the intersection between the person, their skill repertoire, and the requirement of the environment becomes even more critical. For example, a student may be more willing to independently apply deodorant if they personally pick the form (e.g., spray, roll-on) of the deodorant and its scent. TThis is an example of programming at the intersection of the individual; how deodorant feels or smells to them when applied can turn a meaningful but non-preferred skill into a meaningful, preferred skill.

As an educator or other professional, this should not be an alien concept as you practice it every day in your own life. For example, when you go to check out at the supermarket, there exists an intersection between your skill set and the environment: do you use self-checkout or go to a cashier lane? If you have only a few items, or you feel comfortable with self-checkout you could go there. Similarly, if you do not like waiting in line at the checkout, you may choose to do your shopping before going to work when there are fewer people at the supermarket. Either option represents a personal response to the intersection of the environment, a person's skill repertoire, and personal preferences.

For students with autism, particularly those with a limited skill set indicating preferences, the relevant intersections may be difficult to identify. In terms of meaningful curriculum, however, this only serves to further highlight the importance of individually determined CBI starting early on. For example, a goal to teach a person to respond with their current location when texted by a known person has value in terms of a personal safety goal, but initially may have limited meaningfulness to the individual. If that same individual loves chocolate cake, beginning instruction by sending them texts telling them where to find a piece of chocolate cake may make the process of "responding to a text" more valuable to the individual and, therefore, more meaningful. This systematic process is not easily accomplished, however, if the skill is to maintain, it has to acquire some personal meaning.

The simple truth is that if instruction in meaningful goals does not happen when an individual is in school, it is unlikely to ever happen, given the highly limited availability of supports and services in adulthood (Shattuck et al., 2020). Goals must be socially valid to the student, support team, and the immediate community in order for instruction to be successful (Schwartz & Baer, 1991). Social validity, as outlined by Wolf (1978), is the degree to which programming is acceptable to the student and to others. Ideally, society should be validating programming at every step of the planning process, including the goals selected, the procedures used, and the outcome of programming (Stokes & Baer, 1977; Wolf, 1978). The regular assessment of social validity can, and should, include the individual receiving services to whatever extent possible, as well as parents, caregivers, and other community members (Stokes & Baer, 1977). Meaningful programming that has been created can be validated using a number of already established measurement tools (e.g., Bernstein, 1989; Fawcett, 1991; Gresham & Lopez, 1996; Kazdin, 1980), with adjustments being made to programs as needed based on their results. A recommended beginning to identifying social validity early on is to use person-centered planning.

Person-Centered Planning

Person-centered planning is a process designed to allow individuals with disabilities to participate more actively and directly in their transition planning including attention to the person's preferences for a life they would consider to be meaningful based on their individual strengths, abilities, aspirations, and preferences (Collings et al., 2019). Person-centered planning has been found to promote more positive adult outcomes for people with various disabilities labels (Robertson et al., 2007). Autistic youth, however, can experience difficulties in participating due

to communication and social deficits (Hagner et al., 2014). As such, embedding instruction in self-determination skills within a curriculum is an important component of individualized, person-centered intervention, especially because these skills often do not develop without specific instruction for individuals with disabilities (Stancliffe et al., 2000; Wehmeyer et al., 1996). As Wehmeyer and Abery (2013) stated, "Self-determined people are, in essence, actors in their own lives, rather than being acted upon" (p. 399). Such individuals make their own decisions, set their own goals, and create plans to meet these goals (Martin et al., 2019). The critical skill of self-determination has been shown to improve the likelihood of meaningful outcomes in adulthood, specifically in the areas of employment, postsecondary education, and independent living (Field et al., 1998; Lachapelle et al., 2005; Powers et al., 2012; Wehmeyer & Schwartz, 1997).

Self-determined behavior, including making personally relevant choices, has also been identified as a core dimension of quality-of-life and happiness (Shalock & Verdugo, 2012, Wehmeyer & Abery, 2013). Any meaningful curriculum should therefore prioritize communication skills instruction while concurrently assessing various indices of happiness (e.g., smiling, laughing, yelling while smiling) as well as unhappiness (e.g., frowning, crying, yelling without smiling) to determine and honor preferences (Dillon & Carr, 2007; Green & Reid, 1996). Techniques rooted in the principles of applied behavior analysis (ABA) have demonstrated our ability to clearly define and systematically increase, a number of indices of happiness even for individuals with profound multiple disabilities and limited to no communication skills (Dillon & Carr, 2007; Green et al., 1997; Green & Reid, 1996; Ivancic et al., 1997; Lancioni et al., 2002). The fact that data support that practitioners can identify and promote the acquisition of behaviors associated with improved quality of life and happiness, supports an argument in favor of meaningful curriculum and intervention on a practical and professionally ethical basis.

How to Teach: Effective Interventions for Meaningful Goals

Instruction in meaningful curricula is provided in the environment in which the skill is most likely to be used (Gerhardt et al., 2013). Skills targeted for acquisition that appear to be meaningful, lose that designation when taught outside of the relevant context (Brown et al., 1976). Practitioners cannot solely teach skills in classrooms or school hallways and hope for the best. For example, teaching an individual to cross the street while in the classroom is unlikely to generalize to the community without additional instruction in the community. As individuals get older, the proportion of instruction delivered in schools and clinics should be reduced and replaced to the greatest extent

possible with instruction in the context in which the skill will ultimately occur (Bahry et al., 2022a; Gerhardt & Bahry et al., 2022; Gerhardt et al., 2013). Long-term planning is crucial because individuals will only be in the classroom for a finite number of years, but will be out in the real world for the rest of their lives.

Because adaptive behavior skills, in general, tend to be complex skills, they may require potentially complex intervention. In those cases, interventions based on the principles of ABA (Baer et al., 1968) represent a set of evidence-based strategies with documented effectiveness in promoting the acquisition of adaptive behavior skills. These interventions include, but are not limited to, modeling, chaining, shaping, differential reinforcement, token economies, behavioral momentum, self-management, and functional communication training (FCT; Gerhardt & Lainer, 2011).

Respectful Intervention and Meaningful Curriculum

A meaningful curriculum is an essential component of a future life of dignity and respect. As Brown and colleagues (1979) noted, "The more functional skills individuals with disabilities have in their repertoires, the more they can do for themselves, the more privacy, choice and dignity they have and the fewer social, emotional, financially and other pressures they place upon others" (p. 4). Continuously evaluating goals to promote the most independence possible by imposing the fewest restrictions necessary to maintain safety is, therefore, recommended. Winett and Winkler (1972) warned against, "a rigid preoccupation with order and control and where children are required to be still, to be silent, and to obey" (p. 499). This warning is of increasingly greater importance as individuals age across the school years. Individuals have a right to instruction and support in exercising these freedoms, such as the right to choose and refuse and to make decisions about their goals and instruction (Bannerman et al., 1990).

Respectful intervention also includes ensuring that practitioner behavior, including the language used during instruction, promotes dignity. The way practitioners speak and behave toward the individual they support is of central importance in the instructional process. Recommendations include using language that the individual and/or their family prefers (e.g., person-first vs. diagnosis-first language), speaking directly to the individual when in front of them instead of about them, avoiding pejorative language (e.g., "low-functioning"), and speaking about people in a normative way (e.g., using respectful language like Ms./Mr. if it is customary in a given context; Reid et al., 2017). The form of respectful intervention needs to continually evolve to reflect the age of the student or client.

Providing intervention that is respectful of the learner also includes obtaining assent to treatment. While assent is considered an ethical obligation of many professionals including behavior analysts (BACB, 2022), as well as within medicine (Olszewski & Goldkind, 2018; Bakić-Mirić & Bakić, 2008) it is typically not well studied and difficult to define. Assent may be defined using terms like therapeutic alliance (e.g., Goldiamond, 1974) or rapport, but however defined, assent should include both vocal-verbal measures as well as behavioral indicators of agreement to intervention. While there is much work to be done in the development of methods of measurement of assent (Morris, 2021), as well as recommendations regarding how often to obtain assent and how to manage dissent in required intervention, the increased focus on, and discussion about assent in intervention is important and encouraging.

Dignity of Short-term and Long-term Risk

Within the context of a meaningful curriculum, individuals on the spectrum should be afforded what is known as the dignity of risk. Appropriate and reasonable risk-taking can and should be incorporated into a meaningful curriculum. For example, an individual will not acquire the skills necessary to independently navigate a mall if the instructional opportunity is never provided under the guise of personal safety or the absence of any advocacy for the skill to be taught. For some individuals with disabilities, concerns about balancing risk and benefit may be minimized when staff are well-trained in the assessment process (e.g., Driscoll et al., 2022). However, not providing instruction in meal preparation due to the possibility of the person burning themselves on the stove fails to take into account the frequency that neurotypical peers burn themselves or their food during cooking. Withholding access to risk is a way of infantilizing individuals with disabilities (Perske, 1972). As individuals move through school and, eventually, enter adulthood, practitioners need to include instruction in the competencies associated with managing dignity of risk to whatever extent possible while minimizing the possibility of harm or trauma. Clinical judgment (e.g., Leaf et al., 2019; Leaf, et al, 2016) including an in-depth understanding of the individual's learning history, family concerns and preferences, and individual preferences should be used as a guide.

Currently, the majority of adults on the autism spectrum remain dependent on their families and/or providers for the management of their hygiene, medical care, finances, home, and living, and daily living tasks (e.g., Howlin & Magiati, 2017; Roux et al., 2015; Shattuck et al., 2020). Adults with disabilities who live in staffed residences and attend day programs have less emphasis placed on highly qualified staffing support (Lowe et al., 1998; Gerber et al., 2011; Smidt et al., 2007;

Gormley et al., 2019) and some studies have shown that psychotropic drugs are frequently and excessively prescribed to manage challenging behaviors of adults diagnosed with autism with comorbidity of intellectual disabilities in residential settings (Robertson et al.2000; Deb et al., 2015; Bowring et al., 2017; Lim et al., 2021; Felce et al., 2011). Unfortunately, adults with disabilities are not often making decisions for themselves due to their perceived capacity, which is described by McSwiggen and colleagues (2016) as a judgment about the intellectual, decisional, effective, and practical skills to make a particular decision for a person's life, health, and wellbeing. When capacity is determined to be insufficient, a legal guardian is often tasked with making decisions on the behalf of the individual (Dudley & Goins, 2003).

Increasing independence in skill areas such as communication, safety, medical interventions, hygiene, meal planning and preparation, budgeting, and other useful skill domains can help support individuals to lessen or completely avoid dependency on others to make decisions for them in adulthood (i.e., build their capacity to make decisions themselves). In building these skills, individuals in supported environments can begin to take back independence and subsequently reduce relinquishment of decision-making to guardians, residential care providers, staff in workspaces and/or day programs, and even family members.

Systems-Based Approach to Meaningful Programming

Creating meaningful programming requires a sometimes significant shift in the current practices of a given learning environment. Significant changes in organizational settings often require a systems-based approach for success (e.g., Standen, et al, 2020). In order to develop a process that can support this, intentional moves generally need to be made at a myriad of levels of a school or school district (i.e., classroom, teacher, administration)

The administration level training on meaningful curriculum, including the practices discussed in this paper, should focus on school principals and/ or executive directors. Gaining buy-in from director-level professionals is critical to promote a top-down implementation process. These strategies can help to develop a positive and inclusive school culture that prioritizes long-term outcomes.

The teacher level may be one of the most important pieces, given that this is the level where goals are written. Coaching and feedback can help to improve and shape behavior in teaching practices (Gavoni & Weatherly, 2019), which reasonably could include practices related to a focus on meaningful programming. The educational team supporting the teacher needs to play a role in identifying meaningful goals and the development of systems for data-based decision-making.

At the classroom/direct-care level, there are many practitioner (e.g., assistant teachers, paraprofessionals) behaviors that contribute to the practice of meaningful programming.

When instructors have the perception that they are effective in their teaching practice, this has been shown to have a large effect size related to positive outcomes for students (Hattie, 2013). Instilling the perspective that programming developed is going to meaningfully affect individuals' lives long-term can be a helpful addition to this perception.

Summary

The goal of any meaningful curriculum is to increase the student's personal independence across multiple environments. Personal independence can be defined as the degree of congruence (or match) between the skills in an individual's repertoire and the social, communication, social, safety, and mobility demands of the environment in which they live, work, or play. Typically developing individuals acquire these skills through a combination of in vivo modeling, shaping, chaining, trial and error, etc. Some more "specialized" skills (e.g., riding a bike, playing an instrument, doing the backstroke) may require a degree of formalized instruction combined with ongoing practice. For most people with autism, however, that naturalistic combination of processes is generally insufficient to acquire even basic skills.

Research (e.g., Dell'Armo & Tasse, 2019) indicates that individualized instruction in skills collectively referred to as adaptive behavior is associated with more positive outcomes in adulthood. Adaptive behavior, however, is an incredibly complex and diverse array of skills and behavioral competencies, the boundaries of which are defined by the intersection of age in years and the physical, geographic, socio-cultural, economic, personal, and health-related demands of the environment. This is at the core of meaningful curriculum and respectful intervention.

Various aspects of a meaningful curriculum and respectful intervention have been laid out in some detail earlier in this paper. However, there is a meaningful curriculum "hack" that has not been discussed, and that is the use of the phrase "in order to." When writing instructional goals or objectives end the goal with "in order to" and then complete the sentence. For example, Jeremiah is a fictional 13-year-old who lives in a rural community. Jeremiah has co-occurring diagnoses of autism and an ID. An instructional goal for may be "Jeremiah will independently ride a 2-wheeled bicycle for a minimum of 60-minutes." As that stands it would appear to be a very time-intensive instructional

goal. However, if we add a completed "in order to," we end up with, "Jeremiah will independently ride a 2-wheeled bicycle for a minimum of 60-minutes in order to join his family on long bike rides and promote a healthy lifestyle as he ages." This addition explains in plain language why this goal could be considered meaningful to Jeremiah.

On the other hand, if Jeremiah had the goal, "Jeremiah will balance his checkbook using the bank provided ledger and a calculator in order to…" In order to what? To do something in the most difficult way possible when using an app or downloading an account statement online would provide the same outcome much more quickly and easily? Just as importantly, assume Jeremiah masters the calculator goal, where does the skill go next? Does he report a negative balance to a parent? Does he advocate at the bank to correct their error? Or, maybe, he then transfers money from one account to another to cover the deficit? In any case, the addition of "in order to" works to assist parents, teachers, and other educational professionals to identify initial goals and propose the long-term application of the goal in a meaningful way. As was stated earlier, this is presented as a hack and not a fool-proof method. Neither should it be considered a substitute to the recommendations provided earlier in this paper.

Effective intervention requires the merging of evidence-based practice and intervention with individualized, meaningful curriculum applied in the right context. While the concept of meaningful curriculum has significant face validity (i.e., it makes sense), the research base in support of this approach remains at an early stage. However, until that research is available, it is probably worth repeating that "teaching the wrong skills well is no better than teaching the right skills poorly." In general, the field of education and related services is good at increasing skill proficiency. Now we need to be proficient with targeting the right skills.

Footnotes

[1]A note about terminology: throughout this paper, the terms "autism," "on the autism spectrum," "ASD," "person with autism," and "autistic person" are used interchangeably. While the authors recognize that amongst the clinical, medical, and neurodiverse community there are preferences and conventions in terminology use, the selection of terminology in this paper is based on grammar and stylistic needs and does not reflect a particular terminological intent.

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