Opportunities to Learn

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TASH2019

PHOENIX
ARIZONA
DECEMBER 5-7

ABOUT THE 2019 CONFERENCE

The TASH Conference brings together self-advocates, family members, advocates, professionals, researchers, providers and other allies to gain information, learn about resources, and connect with others across the country to strengthen the disability field. This year’s conference theme “#tash2019: Building Diverse and Inclusive Communities” reminds us that equity, opportunity, and inclusion relies on the input of broad perspectives and experiences.

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Professors / Researchers - 14%
Students - 12%
Special / General Educators - 12%
Adult Service Providers - 11%
Government / Public Policy Professionals - 10%

SESSION TOPICS

Inclusive Education / PBIS - 40%
Community Living, Employment, Transition - 40%
Self-Advocacy, Recreation & Leisure, Human Rights, Diversity, Communication Access - 20%

SESSION FORMATS

Research (i.e. Case Study, Structured Debate) - 44%
How-To - 40%
Personal Experience/Story - 16%

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EARLY-BIRD REGISTRATION DEADLINE IS FRIDAY, SEPTEMBER 6, 2019.
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More Than Just Yes or No

High expectations and the presumption of competence are core values of TASH and fundamental components to assuring that people with the most significant disabilities have rich and robust opportunities to learn (OTL) and grow. This issue of TASH explores the challenges that students with disabilities, parents, and teachers experience when confronted with multiple barriers to equity, opportunity, and inclusion. Access to a free, appropriate public education (FAPE) for all students with disabilities as a civil right began with the passage of P.L. 94-142 (now I.D.E.A.) in 1975, the same year that TASH was founded. Guaranteed access, however, has not always resulted in instructional intent that is based on high expectations. The promise of the Supreme Court’s Endrew F. decision is that schools must set and implement more demanding instructional goals and strategies. In “The Opportunity to Learn as Guidance for Free Appropriate Public Education,” Debra Taub and Meghan Cosier, describe an evidence-based framework for using OTL to ensure FAPE in light of the Supreme Court’s decision.

The creation of higher standards for all must, by necessity, include the development of all students’ ability to demonstrate their comprehension and mastery of instructional content. Mere exposure to any instruction is insufficient unless students have the individualized support they need to communicate and demonstrate their understanding of the concepts presented. For students with significant disabilities, this starts with support and access to communication as an integral component of their educational plans. As Erin Sheldon explains in her article, Tell Grandma thank you,” this support must also go further than only having the student reliably provide a simple yes or no response.

We know that cognitive development is fluid. Over the past 40 years, research has continued to generate evidenced-based practices that consistently demonstrate the capacity of all individuals to grow and develop when they are given the opportunity to learn. The acknowledgement of this ability compels the adoption of flexible learning environments, using best practices that accommodate individual learning differences and requires reconsideration of the basic assumptions of what any given individual is capable of gaining as well as contributing. Full access to the general curriculum can only begin when everyone involved believes that everyone has everything to gain from the experience.

Letter from the President of the Board of Directors and the Executive Director

Ruby Moore, President of the Board of Directors
Ruthie-Marie Beckwith, Ph.D., Executive Director
Introduction
By Guest Editor Deborah Taub, Trinity Washington University

We are pleased to present the latest issue of TASH Connections. This issue’s theme focuses on opportunity to learn (OTL) for students with significant disabilities. We define OTL as students having access to the general education standards through well designed instruction and assessment built upon a framework of Universal Design for Learning (UDL) and individualized content and supports. As we have known for decades, when a person’s basic needs, such as feeling safe, are not met it is difficult to learn. Indeed, research has been shining the light on the widespread emotional, biological/physiological, cognitive, and social effects adverse childhood experiences may have on cognition, behavior, and social/emotional growth (Bethell, Newacheck, Hawes, & Halfon, 2014; Dowd, 2017; Plumb, Bush, & Kersevich, 2016).

In order for students to have OTL instruction needs to connect what we want and expect students to know and do with what they are actually taught, and both of these things need to be reflected in what is assessed. These assumptions seem like logical expectations for our school systems around student learning, and yet, we know that for students with significant disabilities all too often these pieces are unconnected, disjointed, and inaccessible. (Taub, Apgar, Foster, Ryndak, & Burdge, in press; Polikoff, 2015). At the same time, students with significant disabilities have additional barriers to instruction, materials, and curriculum such as the lack of a robust communication system, a lack of universally designed curriculum, materials and instruction, and the need for additional supports and individualized instruction that provide equity, access, and progress in and out of school.

Low expectations, lack of time spent on standards-aligned instruction and barriers to general education classes and natural contexts significantly limit students’ OTL (Taub, McCord, & Ryndak, 2017; Soukup, Wehmeyer, Bashinski, & Bavaird, 2007). Barriers to OTL may not be immediately seen, but they exist when students do not understand the unwritten social rules that underlie social and academic interactions.

This issue brings together several of these OTL components for practitioners, families, self-advocates, and others working toward the dream of full equity for all people regardless of race, ethnicity, gender, sexuality, socio-economic status, religion, ability, communication method, or narrow constructs of “normal.” Using this framework, we begin this issue by examining a familiar struggle: the idea of a Free and Appropriate Public Education (FAPE) and the many issues and court cases that argue what exactly FAPE means. In the Supreme Court’s response to Endrew v. Douglas County, Chief Justice Roberts states, “a student offered an educational program providing ‘merely more than de minimis’ progress from year to year can hardly be said to have been offered an education at all.” This issue begins to scrutinize the idea of whether a student can be said to have OTL if all of the components of OTL are not in place. To begin, Deborah Taub and Meghan Cosier examine how to evaluate FAPE under the OTL framework and in light of the Supreme Court’s Endrew F. decision. This decision states that a student’s instructional program is more than the student merely passing time in a classroom and must include working toward ambitious and
meaningful outcomes. As a whole, TASH and the authors in this issue define meaningful outcomes as “a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life” (https://tash.org/about).

Next, we delve into one of the most important aspects of OTL: communication. Erin Sheldon, a gifted literacy and language professional development provider and mother to a child who uses AAC, provides a thoughtful piece entitled, “‘Tell Grandma thank you’: Supporting autonomous communication for students learning to use AAC.” In this piece, she details how communication is a fundamental right and the very foundation of OTL and yet, too often, our focus on teaching students with communication needs is not about building communication, but rather obedience. This article explores current trends in teaching AAC and ways to better support communication and thus OTL for those working on building a robust communication system.

We move from this foundation to another fundamental requirement of OTL: the Universal Design for Learning (UDL) framework. This framework is grounded in the idea that there is no mythical “normal” student for whom we should be planning and developing instruction, materials, curricula, and schools, but rather a reality where there is a range of human diversity. When we begin to plan for that diversity we have a stronger chance of creating successful educational systems. Stephanie Craig and Sean Smith provide an excellent primer on UDL and the value of conceptualizing learning around this framework. Additionally, they provide some practical steps practitioners may take to begin implementing UDL in their own schools and classrooms.

Shifting our focus from policy and overarching elements related to OTL, Jean Clayton, Jamie Phlegar, Charlene Turner, and Elizabeth Summers delve into how district and school decisions about curriculum may create or remove barriers to OTL. They focus on alignment across standards, instruction, and assessment in science education as a model to evaluate classroom curriculum and instruction across content areas. We are particularly pleased to see the focus on science instruction highlighted in this issue as too often students with disabilities are not exposed to the inquiry-based and student-driven science instruction expected by the Next Generation Science Standards.

However, a robust communication system UDL, and academic alignment are insufficient to ensure access, equity and progress in the general education curriculum for students with significant disabilities. As Amanda Raymond and Judy Endow illustrate in their articles, for students with significant disabilities, both academic and hidden curricula are important to long-term success. Judy Endow provides an example from her own experiences as a person with autism for considerations about potential barriers to OTL for some students. Her examples of how she thinks demonstrates the importance of using UDL and additional individual considerations in order to provide opportunities for all students. Amanda Raymond’s piece on the imperative of inclusion illustrates how self-contained classrooms and schools automatically create barriers to OTL. She highlights aspects of the hidden curriculum such as making friends, learning language and communication skills, and understanding the unwritten rules of socialization for students to have complete OTL. Finally, our last article by the team of Barol and Focht-New examines barriers from an individual’s lived experience within a system that too often imposes trauma in our well-meaning attempts to provide an education and meaningful outcomes.

Bringing together this wide-range of articles under the umbrella of OTL illustrates the intense scope of what is expected under an educational system that expects more than a student sitting in a room passing time until graduation. These articles also demonstrate the power of individuals to remove and reduce barriers to opportunities. In order to be successful at building sustainable inclusive systems that support equitable OTL for all students we must address big picture issues such as how schools implement and interpret “Free and Appropriate Public Education” as well as individual issues such as what strategies are removing barriers and which ones are unintentionally creating barriers. All students need to have a safe and welcoming environment that supports equitable access to instruction. This access is only possible if students feel physically and emotionally safe and are able to access, understand, and demonstrate their knowledge of both the hidden and academic curricula. The framework of OTL as outlined through this issue provides a strong starting point for helping build better postsecondary outcomes for all students, including those with significant disabilities.
Introduction

References


Opportunity to Learn as Guidance for Free Appropriate Public Education (FAPE)

By Deborah Taub, Trinity Washington University and Meghan Cosier, Chapman University

A Free and Appropriate Public Education (FAPE) is a hard-fought civil right that remains amorphous and, for some, out of reach (e.g., Endrew F. vs. Douglas County School District). “Gray” areas of the law and regulations remain open for interpretation thus leaving a significant lack of uniformity in implementation of the law (ibid). This lack of uniformity results in some school districts denying FAPE to students with disabilities because the students are not receiving access to general curriculum in the Least Restrictive Environment (LRE) and/or their Individualized Education Programs (IEPs) are not developed in accordance with legal guidelines, or fail to confer educational benefit (e.g., Endrew F. vs. Douglas County School District [Endrew F.], 2017) Given the widespread issues associated with federal and state policy implementation (e.g., United States vs. Georgia, 2017; Endrew F., 2017) we propose a framework based on the concept of Opportunities to Learn (OTL), which administrators and parents may use to evaluate practice, documents, and policies for their ability to confer FAPE to students with significant disabilities.

What is FAPE?
The Individuals with Disabilities Act (IDEA; 2004) defines Free Appropriate Public Education as an education that is provided at public expense, meets the standards of the state educational agency, includes an appropriate pre-school, elementary, or secondary education, and is provided in compliance with the IEP. The implementation of a FAPE, and ideas about how FAPE is enacted, have been argued in the courts with the United State Supreme Court case of Rowley v. Board of Education (1982) setting the standard for interpretation of this IDEA principle until a recent Supreme Court case again took up the issue of
Opportunity to Learn as Guidance for Free Appropriate Public Education (FAPE)

FAPE. The decision in the landmark case of Endrew F. vs. Douglas County School District (2017) suggests that access to the Least Restrictive Environment can, in fact, impact a student’s opportunity to receive a FAPE. In essence, lack of access to general education curriculum and contexts can prevent equal educational opportunity. Furthermore, the decision suggests that the IEP must be “appropriately ambitious” and allow the student to make “meaningful progress” in the general curriculum (Endrew F., 2017). The ruling by the Supreme Court states, “The IEP provisions reflect Rowley’s expectation that, for most children, a FAPE will involve integration in the regular classroom and individualized special education calculated to achieve advancement from grade to grade.” (p. 13). This recent decision requires us to evaluate the practical implementation of FAPE for all students with disabilities, particularly those with complex support needs.

What is OTL and How is It Implemented?

OTL has been used to examine the validity of standards-based reform measures that have been premised on the idea that increasing the rigor of standards, teaching those standards, and measuring student achievement of those standards will improve educational systems (Taub, McCord, & Ryndak, 2017). The basic rationale is that students cannot be expected to make progress in content they have not been taught, nor can they be expected to make progress if the expectations, teaching, and assessments are not connected to each other. There should be alignment between the intended curriculum (the standards), the enacted curriculum (what is taught), and the assessed curriculum (typically identified as large-scale assessments). Figure 1 details the components needed for students with disabilities to have true access to OTL.

This conceptualization makes clear the six major areas that are often lacking for students with severe disabilities who tend to be educated in segregated settings. These components include: 1) students in settings where there is both allocated and instructional time that focuses on the general curriculum as defined by the state academic standards, 2) students’ enacted curriculum is aligned to the intended curriculum 3) teachers are using quality instructional strategies that are proven to support the students they teach, 4) students are engaged in the instruction that occurs in the classroom, 5) students have the communication system in place to receive and respond to what they are learning, and 6) instruction includes ecologically individualized goals that are fundamental to preparing “the child for further education, employment, and independent living” (34 CFR 300.1(a)] [20 U.S.C. 1400(d)(1)(A)].

Administrators, teachers, and parents may apply this framework in order to ensure access to general education curriculum and contexts. For example, administrators can utilize this to address any gaps associated with a student’s OTL. This includes providing clear guidance on writing standards-based IEPs and ensuring that IEPs reflect access to standards. Furthermore, if students are not making progress on standards-based IEP goals, administrators can bring in additional instructional coaches to review the data and instructional strategies to evaluate instructional practices and supports to ensure meaningful access to standards-based instruction. Lastly, they may provide consistent time for general and special educators to collaborate on instruction and set priorities for all teachers to receive ongoing training on deconstructing the standards and making standards-based instruction accessible to students with complex support needs. This ensures that teachers are using quality instructional strategies that promote access to standards-based instruction.

Using OTL to Ensure a FAPE

The following crosswalk illustrates the legal concept of FAPE within the Individuals with Disabilities Education Act and how components of OTL could be used to address each concept. Some legal concepts, such as “provided at public expense” are not included in the chart as OTL does not directly address that specific concept.
## Table 1. IDEA Concept and OTL Framework Alignment

<table>
<thead>
<tr>
<th>IDEA Concept</th>
<th>OTL Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAPE defined as:</strong></td>
<td></td>
</tr>
<tr>
<td>Education services designed to meet the individual education of needs of students with disabilities as adequately as the needs of nondisabled students are met</td>
<td>In order to access the intended curriculum students with disabilities need:</td>
</tr>
<tr>
<td>The education of each student with a disability with nondisabled students, to the maximum extent appropriate to the needs of the student with a disability</td>
<td>to be in general education contexts with appropriate supports and accommodations with similar amounts of allotted time for each area of instruction (e.g., math, science, literacy)</td>
</tr>
<tr>
<td>Preference for general education</td>
<td>individualized considerations for the best way to maximize time students spend engaged with the intended curriculum</td>
</tr>
<tr>
<td></td>
<td>to have a communication system that allows them to receive and respond to the information.</td>
</tr>
<tr>
<td></td>
<td>have individualized ecologically identified goals that allow them to actively engage with instruction, materials, and content in the least restrictive environment</td>
</tr>
<tr>
<td></td>
<td>instructional methods that are based in best practices and provide access to the full range of concepts and content of the intended curriculum (e.g., reading instruction includes all five components of literacy instruction)</td>
</tr>
<tr>
<td></td>
<td>universally designed and scaffolded curriculum, instruction, and materials to support students’ demonstrating a range of depth of knowledge</td>
</tr>
<tr>
<td></td>
<td>instruction that covers the breadth and depth of the intended content</td>
</tr>
<tr>
<td>Evaluation and placement procedures established to guard against misclassification or inappropriate placement of students, and a periodic reevaluation of students who have been provided special education or related services</td>
<td>What is taught in the classroom must closely align with the general education standards</td>
</tr>
<tr>
<td></td>
<td>What is assessed for accountability purposes must match what the state has identified as important for all students to know and do</td>
</tr>
<tr>
<td></td>
<td>Assessment information must be comprised of formative assessments that inform instruction, progress monitoring, and any large-scale assessments or standardized assessments</td>
</tr>
<tr>
<td>Meet the standards of the educational agency</td>
<td>Defined as the intended curriculum outlined by the state for all students</td>
</tr>
<tr>
<td>In conformity with the IEP</td>
<td>Includes the individually identified ecological goals from the students’ IEP embedded into the intended curriculum</td>
</tr>
</tbody>
</table>
Opportunity to Learn as Guidance for Free Appropriate Public Education (FAPE)

**Least Restrictive Environment:**

<table>
<thead>
<tr>
<th>Preference for general education</th>
<th>Student has access to general education contexts with appropriate supports and accommodations with similar amounts of allotted time for each area of instruction (e.g., math, science, literacy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IEP includes a statement of progress in the general education environment, reason for removal from general education</td>
<td>This statement includes a detailed description of the student progress in the general education environment based on access to this environment and grade-level standards-based instruction. Reasons for removal must be detailed and show a concerted effort to address how removal will be faded and how the student will be reintegrated into the general education setting.</td>
</tr>
<tr>
<td>IEP includes a statement with supplemental aides and service and modifications and support for school personnel for student to show progress in general curriculum.</td>
<td>Student always has easy access to a communication system Communication system is robust enough to respond to and ask questions about the intended and enacted curricula. Related services are provided to help a student access content and daily routines within general education contexts. Instruction allows for multiple means of engagement, action and expression, and representation.</td>
</tr>
</tbody>
</table>

Example of Application of OTL to Ensure FAPE

Mariam is a kindergartener with extensive support needs who has been included with her peers without disabilities and her Individualized Education Program (IEP) team is now discussing options for first grade. Mariam has made lots of gains during her Kindergarten year, while also developing some strong friendships with her peers. The students and Mariam, liked to talk about her picture cues on the eye gaze board and would play iPad games together during free-time.

At the IEP meeting, it seemed that everyone at the table had already made up their minds about Mariam’s future placement for the first grade and they were not in agreement. The school team was concerned about her low-performance in comparison to her non-disabled peers, her need for extensive and pervasive support needs (i.e., personal care, mobility), and the fact that Mariam’s learning goals may be different than those addressed in a general education setting. As a result, the school team recommended that placement in one of the currently available specialized programs would be Mariam’s least restrictive environment (LRE) and the best way to support Mariam’s access to a free appropriate public education (FAPE). Mariam’s parents, however, believed that Mariam was best served in the general education classroom.

The IEP team discussed the academic, social, and self-help gains Mariam had learned this year, including increased verbal word use, more time awake throughout the day, increased choice-making, being able to answer direct recall questions from a story using three picture response options, independently turning the pages of books, and learning to use the iPad and classroom computer for both leisure and learning activities. Mariam’s parents agreed that these goals were an important part of Mariam’s education, however, they viewed them as being more meaningful and applicable because they were done within the context of a general education setting. They believed that part of Mariam’s FAPE was that she needed multiple and consistent opportunities to learn grade-level content and skills and that these opportunities would be more prevalent in a general education context. Ultimately, it came down to the questions: a) How have legislative, judicial, and executive branches of the government, articulated and shaped FAPE?, and b) How can school administrators and principals ensure that they provide each student with extensive and pervasive support needs with an education that prepares them for further education, employment and community living? Table 2 below shows how the OTL framework is applied to the Miriam’s situation and the decision-making processes surrounding placement and access to general education contexts.
### Table 2. Application of OTL Framework

<table>
<thead>
<tr>
<th>OTL Framework</th>
<th>Adjustments to increase Miriam’s alignment to the OTL Framework</th>
<th>The effect on OTL should Miriam move out of the general education context</th>
</tr>
</thead>
<tbody>
<tr>
<td>In order to access the intended curriculum students with disabilities need:</td>
<td>Continue to be in general education contexts with appropriate supports and accommodations with similar amounts of allotted time for each area of instruction</td>
<td>Research has shown that compared to students in inclusive contexts, students in segregated settings:</td>
</tr>
<tr>
<td>☐ to be in general education contexts with appropriate supports and accommodations with similar amounts of allotted time for each area of instruction (e.g., math, science, literacy)</td>
<td>Review Miriam’s schedule and her personal needs (e.g., sleep, hygiene) to minimize the amount of time she is not engaged with peers and content</td>
<td>☐ do not have the same amount of time spent on content (Davis, 2015; Soukup, Wehmeyer, Bashinski, &amp; Bouvaird, 2007).</td>
</tr>
<tr>
<td>☐ individualized considerations for the best way to maximize time students spend engaged with the intended curriculum (general education standards and curriculum)</td>
<td>Continue to build Miriam’s communication system using core vocabulary to maximize her ability to engage with the intended curriculum and her peers</td>
<td>☐ do not have the same breadth and depth of instructional strategies (Ruppar, Allcock, &amp; Gonsier-Gerdin, J., 2016).</td>
</tr>
<tr>
<td>☐ to have a communication system that allows them to receive and respond to the information.</td>
<td>IEP team develops individualized ecologically identified goals that allow Miriam to engage with instruction, materials, and content, and the hidden curriculum (e.g., turn taking and conversational goals, foundational academic skills such as identifying numbers)</td>
<td>☐ do not have the same quality and frequency of communicative interaction (Foreman, Arthur-Kelly, Pascoe, &amp; King, 2004).</td>
</tr>
<tr>
<td>☐ have individualized ecologically identified goals that allow them to actively engage with instruction, materials, content, and the hidden curriculum in the least restrictive environment</td>
<td>Use an IEP matrix to identify where the individualized ecologically identified goals are best practiced within daily routines</td>
<td></td>
</tr>
<tr>
<td>☐ instructional methods that are based in best practices and provide access to the full range of concepts and content of the intended curriculum (e.g., reading instruction includes all five components of literacy instruction)</td>
<td>Ensure all teachers are trained in Universal Design for Learning</td>
<td></td>
</tr>
<tr>
<td>☐ universally designed and scaffolded curriculum, instruction, and materials to support students’ demonstrating a range of depth of knowledge</td>
<td>Ensure all curriculum and materials are universally designed</td>
<td></td>
</tr>
<tr>
<td>☐ instruction that covers the breadth and depth of the intended content</td>
<td>Develop IEP goals that are based on standards or clearly help Miriam access the standards and that prioritize the content and skills used to meet these goals</td>
<td></td>
</tr>
<tr>
<td>What is assessed for accountability purposes must match what the state has identified as important for all students to know and do</td>
<td>Similar to above, Miriam’s instruction needs to include equal time on general curriculum (intended curriculum)</td>
<td>Educators who lack content knowledge or special education praxis and have limited collaboration time will struggle to create aligned lessons that are accessible (Quenemoen et al., 2010).</td>
</tr>
<tr>
<td>Assessment information must be comprised of formative assessments that inform instruction, progress monitoring, and any large-scale assessments or standardized assessments</td>
<td>Use multiple assessments to inform the planned and enacted curricula</td>
<td>Special educators do not prioritize the same content and skills as general educators and this knowledge is different than the intended curriculum (Blank, 2012)</td>
</tr>
</tbody>
</table>
Shatterproof is a national nonprofit organization focused on ending the devastation that addiction causes families. The organization was born from a personal tragedy when founder Gary Mendell lost his son Brian to a battle with opioid addiction. The tragedy was compounded by the stigma surrounding addiction that made Gary feel so alone. Today, Shatterproof brings families together to end the devastation of addiction. In addition to state and federal advocacy, the organization engages the public through education, fundraising, and stigma-shattering public events.

In fact, the challenges of American addiction are quite widespread. Shannon Hartley, Shatterproof’s Chief Marketing Officer, notes that alcohol or drug addiction touch about one in three Americans when accounting for family members. A recent government report\(^1\) showed 129 overdose deaths in the United States every day, 61% of which involved opioids, including heroin and prescription pain relievers.

To reverse the epidemic of opioid drug overdose deaths and prevent opioid-related morbidity,” said the report, “efforts to improve safer prescribing of prescription opioids must be intensified.”

Shatterproof agrees. That’s why in 2016, it was focused on the California legislature to enhance utilize of the state’s prescription drug monitoring program.

**Essential Legislation. Uncertain Prospects.**

The bill in question enhanced the state prescription drug monitoring program (the Controlled Substance Utilization Review and Evaluation System, or CURES) to help prevent “doctor shopping”, requiring physicians to query a state database before prescribing certain medication. The goal is to prevent physicians from unwittingly prescribing a drug that a patient has already received or another drug that increases the risk of overdose. “In states that don’t require mandatory querying,” says Hartley, “less than 14% of doctors ever check the database.”

To Shatterproof, the need for the bill was obvious. It’s prospects, however, were not. Amid concerns about outdated technology, skepticism about overregulation, and a lack of public awareness, Hartley says her team believed there was only "a modest probability of success." To improve its odds, Shatterproof led a vigorous grass roots advocacy campaign, including leveraging the Phone2Action platform.

"Phone2Action is a core platform to supporting our advocacy efforts, helping us engage passionate people at a grassroots level.”
Making It Easy To Acquire and Activate Advocates

“We needed a system that was going to make it as easy as possible for citizens to engage,” says Hartley. “A lot of the older advocacy tools required a heavy lift on the advocate to look up their State Senator or State Representative, make a phone call. Phone2Action provided that through a very simple registration.”

The platform made it easy to sign up advocates at publicity events and then activate them during the legislative process. The Shatterproof campaign included lawmaker contacts in key districts, paid Facebook advertising, and even a live event in Sacramento where advocates shared their stories. “We were able to tap into that group because we had done a robust group of advocates coming in through Phone2Action,” says Hartley.

Success: “The Numbers Speak for Themselves”

The campaign’s advocates came from every legislative district in California. 90% of them had never been part of Shatterproof campaigns before. They sent over 1,800 messages to legislators.

In the end, the bill passed\(^2\) with just one dissenting vote, and on September 27th, 2016, the Governor signed the measure into law.

“The numbers speak for themselves,” says Hartley. “It went from less than 50-50 probability to near unanimous support in large part because the legislators heard that this was a really important issue from their constituents.”

For Shatterproof, Phone2Action was a true platform on which to build a successful campaign. “In a very short period of time we were able to engage a really broad number of advocates,” says Hartley. “That’s just not possible with a lot of the other platforms and things that we’ve used in the past.”

Bringing Phone2Action To The Next Battle

Shatterproof’s ambitions stretch far beyond the state of California. Using Phone2Action at the federal level, Shatterproof helped aid the passage of The Comprehensive Addiction and Recovery Act. Next up are states like Georgia, Texas, Arkansas, and Missouri—the only state in the country with no controlled substance database at all.

“Phone2Action is a core platform to supporting our advocacy efforts, helping us engage passionate people at a grassroots level.” The addiction crisis, after all, reaches one in three Americans. And Shatterproof is determined to change that.


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Considerations for Application in a Legal Compliance Context

Ensuring access to general education curriculum and contexts, standards-based instruction, and high quality instructional strategies all align with IDEA requirements of providing a Free Appropriate Public Education in the Least Restrictive Environment. However, we do not intend to imply that following the OTL framework alone will keep schools and districts legally compliant in all areas of FAPE or LRE, as many factors must be considered in terms of compliance with federal and state legislation and regulations. We do posit that using an OTL framework can improve access, instruction, and outcomes in ways that align with IDEA legislation and regulations. Using the OTL framework can support a school’s “good faith effort” (Yell, 2016) to implement a FAPE in the LRE, and help provide effort of such efforts.

Conclusion

It is our charge to advocate for a more clearly defined set of components from which to evaluate the “appropriateness” and “meaningfulness” of the educational services being provided for students with complex support needs. A framework for implementation addresses the current issues with significant variability in interpretation and implementation of federal and local special education related policies (Brock & Schaefer, 2015). OTL provides a clear framework for identifying and evaluating the educational opportunities for students and thus the extent to which their current education is meeting the requirements of FAPE. Furthermore, the elements of OTL provide actionable items for supporting a meaningful education, supporting administrators, educators and parents in putting the policies of IDEA into practice in meaningful ways.

References


“Tell Grandma ‘thank you’”: Supporting Autonomous Communication for Students Learning to Use AAC

By Erin Sheldon, AT Consultant

Introduction

Communication is at the core of human and civil rights. Attend any conference on alternative and augmentative communication (AAC) for speech language pathologists, educators, or assistive technology professionals and you will hear some version of the three essential elements to supporting students with significant communication disabilities: a robust AAC system (Zangari, 2016), core vocabulary (Erickson, 2017), and aided language input (Sennott, Light & McNaughton, 2017). Robust means the communication system or tool itself can convey original messages on a wide range of topics: asking questions, sharing information, telling stories, commenting and expressing opinions, requesting or rejecting, and social etiquette like greetings. Core vocabulary refers to ensuring students have access to a vocabulary of the most frequently used words in the English language so they can construct their own novel messages rather than be limited only to nouns they can request or to pre-programmed whole phrases. And aided language input (also known as partner-augmented input, aided language stimulation, or AAC modelling) is a strategy where communication partners model the use of the AAC system so that the student can observe others communicating in the same modality to which our student has access.

These are all positive developments in how we are supporting communication for students with significant disabilities and complex communication needs. We have considered the tools our students need (a robust AAC system), the vocabulary that allows them to access and engage the curriculum, and the instructional strategies that are evidence-based to teach them how to use the tool and the vocabulary. These three elements are a critical response to decades of readiness standards when we presumed that many students were not capable of symbolic communication, denying access to AAC for generations of students who could not demonstrate prerequisite skills. They are a huge improvement over the overwhelming focus on manding. Applied behavior analysts use the term, manding, to refer to requesting a specific behavior and often dominates communication support for our students. But there is still often one missing piece: the basic understanding that communication is what happens when one person shares an idea the other person did not already know they were thinking.

Parroting vs. Communicating

Imagine an encounter with a person who approaches to tell you your name and what color shirt you are wearing: we would all consider this odd. Stating the obvious or sharing what we already know might be speech, but it is not communication. Similarly, imagine telling your preschooler to thank Grandma for her gift of new socks. He might dutifully say “thank you, Grandma” but Grandma will doubt the socks are truly...
It is communication when our students tell us their own ideas, including the ideas we rather they wouldn’t communicate, such as “NO,” “NOT NOW,” or “GO AWAY.”

appreciated if the message does not feel authentic or spontaneous. Parroting back what we are told to say is obedience, not communication.

Now observe how our students with complex communication needs are taught by the professionals in their lives. Whether these are one-on-one sessions between our students and speech language pathologists, or small group instruction with special educators, or even just meal time support between a student and an educational assistant, we still hear adults directing students to “say ‘I WANT MORE,” or “show me GO” or “Alexis, tell me your name” or “What is your name?” If the student does not respond, we often model how they can say this on their AAC, then wait for them to imitate and repeat what we told them to say. Sometimes we even take their hands and say it for them. We still see educators taking data on how consistently the student correctly made choices expressing his or her preferences, as though we can know with certainty what our students want even when they tell us something different. In the name of teaching communication, we instruct students to state the obvious and parrot back what we tell them to say. Sometimes we even take their hands and say it for them. We still see educators taking data on how consistently the student correctly made choices expressing his or her preferences, as though we can know with certainty what our students want even when they tell us something different. In the name of teaching communication, we instruct students to state the obvious and parrot back what we tell them to say. Then we somehow expect that this instruction will teach them their AAC system is their own autonomous voice to share their own ideas. We remain surprised when so many students seem to perceive their AAC as a tool for work they use to perform for others at school, rather than a tool for their own self-determined voice. And we frequently blame the students for not being motivated enough or capable enough to use the AAC systems we have provided them.

As we plan OTL for our students with complex communication needs, we need to first remember what we all know about communication. It is not communication if we already know the correct answer: that is testing. It is not communication if we tell the person what to say: that is obedience and imitation. It is communication when our students tell us their own ideas, including the ideas we rather they wouldn’t communicate, such as “NO,” “NOT NOW,” or “GO AWAY.” If we understand that communication is when a student conveys her own original thoughts, then we will see more communication in the student who refuses to say “thank you” on cue than in the one who dutifully complies.

Supporting Authentic Communication

There are so many ways that educators, speech language pathologists, and educational assistants are supporting authentic communication in our classrooms. It can be as simple as an educational assistant modelling a student’s AAC system to ask the student if she wants MORE spaghetti or SOMETHING DIFFERENT. Open-ended choices like “something different” put the onus on the support person to list the various options until we discover what the student might be craving. It is never authentic choice-making if our students have fewer choices than their typical peers, or no option to modify the request the way we do with speech. Their speaking peers, for example, can request spaghetti but ask for the noodles to be separate from the sauce.

But our students with complex communication needs are too rarely supported to put conditions on what they have requested. Giving them models to elaborate on HOW they want something shows them how their AAC can influence simple but important things in their day to day lives.

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OTL requires us to problem-solve how our students can access the same educational language environment as their speaking peers. By the time they start school, speaking children have heard thousands of hours of millions of spoken words being combined and recombined to convey countless original thoughts (Hart & Risley, 1995). In contrast, our non-speaking students receive a fraction as many models, even though their task is more complex: to translate words they know from a sound-based language system into the words they can motorically access on a visual-based language system. Creating access to OTL means we have to problem-solve access to an immersive language environment where our students see their visual language system used to convey ideas for learning. How many of us studied a few years of a foreign language but only managed to learn a few phrases? We know the limits of direct instruction when it comes to language learning. We need to ask: have our students who are learning to use AAC had the opportunity to be immersed in their visual language? Without immersion, then we are expecting our potential AAC users to learn a new language with few people to speak it to them, with them, or around them.

Aided language input, or AAC modelling, is a strategy to create an immersive AAC environment in the regular classroom. More
schools and classrooms are adopting peer support arrangements to increase interaction between students and encourage AAC use (Biggs, Carter, & Gustafson, 2017). Again, these strategies must be anchored in the understanding that communication is not imitation or dutiful obedience. For example, I watched peers in one classroom use the student’s AAC to describe the book the class was listening to as “BORING” and “NOT GOOD.” The special educator calmly redirected the students to stay on task and describe the main character, but did not censure these authentic comments. An hour later, the student herself described an activity as “BORING” and requested to do something “DIFFERENT.” This same 6th grade classroom encouraged students to sign up as the “AAC user of the day.” A duplicate of the target student’s AAC system was available for any student to use to communicate; students who signed up kept lists of what they had struggled to say and journaled on the frustrations they experienced when the fast-paced discussion left them behind. They shared their experiences with their whole class to teach empathy for the very real challenges and limitations of using AAC.

Anyone who has ever studied a second language in the classroom knows that direct instruction in a new language is often helpful but rarely sufficient to learn a new language: our brains are wired to learn language while interacting with others in activities and exchanges that are personally meaningful. It is the quality of the interaction, including the number of conversational turns, that determines its efficacy for teaching language (Hirsh-Pasek, et al., 2015). This means that OTL requires us to create personally meaningfully invitations for students to use their AAC - and any other tool at their disposal - to convey their own ideas. As professionals and parents, we can scan through our student’s AAC to reflect what our students are sharing: “You are frowning. I think SOMETHING is WRONG. I wonder if you are FEELING…IRRITATED…or GRUMPY…or maybe even ANGRY. Oh! I saw how you looked at me! I think maybe I am making you ANGRY. Clearly, you WANT me to STOP this activity.” We can look to the words or icons they select and to their response to our own modelled wonderings to see if we are on the right track. But we can only reflect back what they are communicating with their bodies if we are prepared to think about communication as how to support them to share what we don’t necessarily wish they would tell us.

One of the most effective strategies to support OTL for our students learning to use AAC is Gail Van Tatenhove’s (2012) descriptive teaching method. Van Tatenhove encourages educators to shift from the old referential style of teaching, where we ask students questions with only one right or wrong answer, such as “what was the protest that occurred on Dec 16, 1773?” or “what type of rock is this?” When we teach in the referential style, the only way our students can correctly answer our questions is if we program their AAC systems with entire folders of every academic term, such as a folder of rock types or a folder of all the events and people in the American Revolution. This results in unwieldy AAC systems packed with words that are unlikely to be used regularly. Instead, we use descriptive teaching, where we use high-frequency words to show many ways to explain the same concept. We teach our students to use their existing, ordinary AAC vocabulary to understand and share what they are learning. While studying rock types, we can use objects and photos to show our students how to observe and describe what we see: the igneous rock might be SHINY and BLACK while the sedimentary rock is ROUGH and LIGHT. We redefine new vocabulary using words our students can access in their AAC; “representation” might be redefined as “we choose who speaks for us.” While studying the Boston Tea Party, our student might share that protest is when we “SAY NO, SAY NOT LIKE.”

Descriptive teaching is a rich opportunity to engage peers to translate the big ideas of a curriculum unit into ordinary plain language, while creating OTL for our students with significant disabilities. A focus on descriptive teaching creates a more accessible language environment for any student who struggles with vocabulary, language processing, or is an English language learner. We can assess student learning through a variety of means, from asking our most sophisticated AAC users to “tell me about igneous rocks” while asking more emergent students to listen to word options and indicate, compare, or sort which words relate different rock types perhaps even while holding that type of rock.

Summary

Communication is when we create opportunities for our students to share their own authentic ideas. If it is either the right or the wrong answer, then it is not communication. If the content of the message has to be prompted and imitated, then we should question whether it is truly communication. Robust AAC with a vocabulary of core words and an aided language modelling environment are all important but insufficient to support our students to communicate. We must first ensure that we are asking our students to share what we don’t already know they are thinking.
Articles from Our Contributors

“Tell Grandma ‘thank you’”: Supporting Autonomous Communication for Students Learning to Use AAC

References


Universal Design for Learning: Attaining Meaningful Access for All
Stephanie L. Craig, M.Ed., and Sean J. Smith, Ph.D., University of Kansas

Universal Design for Learning (UDL) has emerged as a framework used to guide educators to consider learners, their strengths and struggles, and how to intentionally design a learning environment that supports their learning with inclusive, equitable, and accessible practices (see http://www.udlcenter.org/aboutudl/udlguidelines.) UDL is a framework organized around principles to help educators design learning that is presented and assessed in multiple ways that will engage students, including those who have historically been excluded from access to the general education setting. These three principles are: provide multiple means of engagement, multiple means of representation, and multiple means of action and expression.

The educational system often views students with disabilities and those who struggle through a deficit lens (i.e., they need to be fixed) and pulls them from the classroom for interventions that results in missed social and instructional opportunities. However, students with significant disabilities are often segregated, either into separate classrooms or, at times, different schools, due to the belief that their needs cannot be met in the general education environment. Studies have shown that students with significant disabilities benefit from inclusion (Kurth, Lyon, & Shogren, 2015: Parrette & Blum, 2014) and participation in the general education classroom and curriculum. Educators who use a UDL framework to design goals, instructional methods, materials and assessments, can facilitate inclusive practices by planning for all learners with an understanding that individuals have unique needs and that narrow constructs of academic, social or emotional learning create barriers for students. UDL is a means for educators to reflect on inclusive, flexible, and dynamic practices to break the ceiling of lowered expectations forced on students, especially students who have disabilities.

For a teacher who is interested in UDL, a paradigm shift must happen. This shift often begins with the realization that all students, including those with disabilities, are an asset to the classroom. All individuals bring something valuable to a community of learners. Yet, to realize the inclusion of all learners, educators must examine how their current curricula, content, and often instructional practices are disabling resulting in barriers to learning for a variety of students, which leads to unnecessary remediation and potential identification for special education and segregated classroom placement. To reduce or eliminate barriers to learning, educators must look to intentional design, consider learner variability, and identify barriers in the goals, methods, materials, and assessments addressed in today's classrooms.

In the application of the UDL framework, teachers plan and re-design their classroom environments, materials, and instructional experiences acknowledging learner variability that requires upfront planning to avoid retrofitting to accommodate for a group of students. This front-loading work might be a deterrent for time-starved educators. However, this method of design purposefully plans for all students and ultimately creates opportunities for educators to spend needed time with small groups or individual learners for more intensive instruction. In essence, planning for the variability of students saves time, individualizes the learning experience, limits the need to reteach, and in the end, offers further time to personalize the learning experience for all students. The purpose of this article is to introduce the UDL framework within the context of enhancing meaningful access to the general education curriculum for students with significant disabilities. Our expectation is that when educators spend less time reacting to the needs of students and more time designing and implementing strategies and scaffolding to support autonomous skill development in learners, all learners receive a well-designed education experience.
Barriers and Learner Variability

To meaningfully include students with significant disabilities in the general education curriculum, educators must first appreciate the barriers that exist in our educational environments and instructional practices. These barriers often prevent access to needed supports and intensive instructional interventions required for the success of all learners. What are these barriers? For our purposes, barriers are anything in a learning environment such as goals, instructional methods, materials, assessments or the physical environment that prevent a student from accessing, participating in, or making progress towards learning. These barriers are external to the learner, yet impact their opportunities to learn.

A common barrier to K-12 learning is the expectation of reading at a particular level at a certain age. The phrase “learning to read” versus “reading to learn” is most relevant to contextualize this barrier. Beginning in 3rd-5th grade, classroom instruction is often based on a required reading. Be it the textbook, a novel, short story, web-based material, or similar resource, instruction begins with foundational reading. Asking students to read for context makes sense. As an approach, it offers the educator an efficient means to ensure students have the necessary foundation from which to build through further instruction and hands-on activities. For the non-reader or the student with significant delays in reading, materials provided outside of a student’s instructional level of reading presents a barrier. Their ability to meaningfully participate in classroom instruction is prevented by limiting content to reading. Instead of offering multiple options for accessing the content, the reading requirement is a barrier excluding students from the demands of the general education curriculum. Writing is another common barrier. Often used as a way to demonstrate knowledge, a student’s ability to express themselves might be limited due to the complexity of writing. Instead of offering options to share one’s understanding, writing becomes a barrier limiting a student’s capacity to convey what they know about a given content.

Not all barriers affect cognitive performance. Learning environments can have social or emotional barriers that can hinder a student’s engagement. Transitions, for instance, are a common part of learning environments but can be barriers for a number of students. For example, Kylie has autism and struggles with transitioning if she is not properly prepared and engaged before, during, and after the transitioning experience. Kylie’s class transitions periodically in her 1st grade classroom between centers and among different environments in the school, such as the playground, cafeteria, and gymnasium. If she is not prepared for the transition through visual prompts, audio supports, and other purposeful transition tools, Kylie becomes stressed by the sudden change or the removal of an activity of interest or support. The behaviors that follows, due to the lack of support, cause Kylie to be removed from further learning opportunities. Using the UDL principles to identify and then implement strategies that will give Kylie tools to support her adjustment to transitioning removes the transition barrier. A visual schedule posted in the classroom along with giving Kylie a personal schedule shows her the order of activities. Using a timer alerts Kylie to when an activity will end. A transitioning object or toy can move with Kylie as she transitions to alleviate the anxiety she experiences. Creating a safe and distraction-free environment is the responsibility of teachers. The key lies in knowing students and the perceived threats and possible distractions to their learning.

Increasingly, learning barriers are often confused with learner variability. Although there is overlap between the two ideas, there are distinct differences. Learner variability, for example, describes the knowledge, skills/ability level, and culture that a learner brings to the classroom. Barriers, on the other hand, are designs in the learning environment, the curriculum, and instructional practices that need to be removed to avoid marginalizing learner variability in students.

If efforts to include students with significant disabilities in general education contexts are to be successful, educators must understand and appreciate the learner variability of their students. Recognizing and accepting that the idea of an average learner is a myth is necessary in recognizing that typical instructional practices are fraught with poor design and expectations. If educators approach teaching with the belief that there is variability such as tactile, visual, or cognitive processing among all learners, not only in the methods that they gain knowledge but also in the methods that they interact with information and demonstrate knowledge, then we can ensure that educators will seek ways so that they reach each student where they are, emotionally and academically, to the best of their abilities.

A challenge for learners with significant disabilities is that traditional education targets the average and hopes for the best for those students on the outer margins of learning or who do not learn in traditional ways. Traditional education often blames the learner for failing and excludes those with disabilities, arguing they cannot address typical students and those with significant
Universal Design for Learning

The UDL Framework emerged from the recognition of barriers to learning and the research demonstrating that all learners learn, but differently (Meyer & Rose, 2000). Thus, purposeful design and planning is needed to address the needs of all learners. The framework also recognizes that learning does not occur in a vacuum and that external stimuli can affect the way an individual learns on different days and in different situations (Rose, Rouhani, & Fischer, 2013). Taking into account learner variability, UDL is framed from three principles. Each principle consists of three guidelines with checkpoints to guide the design of goals, methods, materials, assessments and the physical learning environment (please see http://udlguidelines.cast.org).

Principle of Multiple Means of Engagement

The first principle of UDL is organized around guidelines to provide multiple ways to engage and motive students. By providing options to recruit interest, teachers embed multiple ways to recruit interest in learning and create authentic and relevant lessons. Providing options to sustain effort and persistence assists learners to work through challenges and develop skills to nurture the drive to work through challenges. Through providing options to self-regulate, teachers explicitly teach strategies and provide opportunities for learners to learn coping skills to better function in an academically challenging and inclusive learning environment. Designing classroom opportunities according to this principle strengthens the development of motivated and purposeful learners.

Principle of Multiple Means of Representation

The second principle of UDL consists of embedding multiple ways to provide information and content during instruction. By providing options for perception, practitioners provide methods and materials in different forms, such as visual, auditory, and tactile, for students and through multiple media. Providing options for language, mathematical expressions and symbols enables teachers to offer different ways to clarify vocabulary, mathematical expressions and symbols, and consider the understanding of and ways to present languages with diverse students. In providing options for comprehension, educators consider the cultural diversity and/or varied background knowledge of their students and explicitly supply background information and tools to support the understanding of big ideas. Implementing this principle aids the development of resourceful and knowledgeable learners.

Multiple Means of Action and Expression

Teachers who use a UDL framework design options for students to show their learning through different means of expression or action. Providing options for physical action allows practitioners to teach learners how to use multiple tools and respond in class in multiple ways. Providing options for expression and communication embeds choices for students to show what they have learned in ways that are comfortable for the learner. By providing options for executive function, teachers implement strategies explicitly designed to assist learners in goal-setting, monitoring progress and realignment to meet their set goals. This principle, when implemented, promotes the development of strategic and goal-oriented learners.

Learning goals, methods of instruction, materials used for learning, and assessments are examined through the lens of the UDL framework’s principles and guidelines to identify potential barriers, inequities, or inaccessibility for learners. The framework is as applicable from preschool to postsecondary education, since its purpose is to guide educators in designing learning across vastly different content areas. The UDL framework serves as a standard to which all teaching and learning design can be held to ensure that students of varying needs can be successful and accepted as a valuable member of an inclusive environment.

UDL in Action

Let’s consider Alice and Matt, seventh graders having just transitioned from the elementary school experience. Alice has an intellectual disability and a language delay, and Matt has an
intellectual disability. Educated in a segregated self-contained classroom for most of K-6, Alice and Matt are beginning Central Middle School in an inclusive environment. Starting this fall, in stark contrast to their segregation in elementary school, their middle school will now include all students, regardless of ability status, in the general education setting for nearly 80% of their instructional day.

Coupled with this move to an inclusive environment, the new seventh graders are also transitioning to the middle school model where they change classes, have assigned lockers, a host of new classmates, and a plethora of new, possibly anxiety-provoking, experiences. To support these inclusive efforts, building leadership hoped that their adoption of the UDL Framework, initially introduced in the district a decade ago, would reduce barriers and ease this transition for students with disabilities, particularly those with more significant support needs. The district’s UDL efforts have led to a revised standard of learning design for all teachers, who are now evaluated annually through the lens of UDL, including on their teaching methods, materials, assessments, and classroom expectations.

Although UDL becomes the foundation that teachers use to design an accessible and flexible learning environment, teachers still need to be aware that they will need to expand the scope of design for instruction, materials, goals, and assessments for students with significant disabilities through personalized supports and accommodations. However, as teachers become more proficient with addressing the needs of a wider range of learners, fewer redesigns take will place and more students will have access to learning. Furthermore, an environment that embraces and normalizes all levels of ability is a more equitable learning environment.

For Mr. Londeree, Central Middle School’s Academic Resource (formerly Life Skills) teacher, UDL has been part of his planning and instruction since he was initially hired five years ago. Employed as a life skills teacher, the movement to a learning environment focused on inclusive practices is presenting new challenges. Working with his middle school team, the Mavericks, Mr. Londeree and his general education colleagues are working to design goals, instruction, materials, and assessments for all students using the UDL guidelines. The challenge this academic year will be determining if instruction designed using the UDL framework can actually meet the needs of all learners, particularly students with the most significant disabilities who have historically been limited to joining their peers without disabilities only during lunch and physical education.

Beginning in August, Mr. Londeree and the rest of the Mavericks discussed their expectations for all learners, especially Alice and Matt. Participation in an inclusive setting was paramount. Expectations along with methods, materials, and assessments also needed to be designed using UDL. The Mavericks believed that their expectations would be a determining factor on the success or failure of the inclusive experience. With this in mind they determined that building community was important for all students, especially if they were to include Matt and Alice. So, the Mavericks planned a number of experiences where students would need to be resourceful and strategic in obtaining, and offering, assistance within the classroom community.

A plan was put in place for Matt and Alice to participate in group activities with targeted assistance from Mr.
Londeree. At first, Alice and Matt looked to Mr. Londeree for everything. Their elementary experience had reinforced the learned helplessness of looking to the teacher for any and all assistance. To complicate matters, other students in the class hesitated to offer help since Mr. Londeree was in the room. Alice’s difficulty with fluent communication added to students’ reluctance. As the students became more comfortable with each other, Mr. Londeree and the rest of the Maverick teachers modeled how to pace questions or conversation to include Alice and Matt. Students began interacting with Alice and Matt more frequently.

The Maverick teachers along with Mr. Londeree realized that barriers existed in materials that were used in the classroom for numerous students but especially for Matt and Alice. In the English language Arts (ELA) class, seventh graders began reading Touching Spirit Bear early in the semester. Text is a barrier for many students, not only Alice and Matt, who struggle with reading or decoding. Using UDL as a guide to design instructional methods and choose materials, the ELA teacher provided all students with multiple ways to read the book. The novel was available in print and audio versions; it was also available as text and audio on YouTube, which presented the text and highlighted the words as they were read. Alice chose to read the novel on YouTube with a partner in the class, while Matt also chose the YouTube version but wanted to watch and listen by himself with headphones. Both students participated in group discussions about the book, identifying the characters and the big ideas of the plot as their peers added to those ideas with details from the novel.

Providing multiple options for materials in visual and audio forms were embedded in the ELA classes for all students. Examining materials for barriers and using UDL to remove them created an inclusive learning experience for Matt and Alice, who now had access to the same novel as their peers and allowed them to participate in expressing their understanding of the content.

Many of the Maverick teachers offered “bell ringer” activities through “itslearning,” the district’s online learning management system (LMS). These activities encouraged the seventh graders to reflect on the previous day’s learning and report on what they had learned. The teachers designed multiple options for students to comfortably respond to the bell ringer activities: students could a) record audio or video responses; b) type their responses; or c) respond with another student as they reflected together. These options allowed Matt, who had difficulties with fine motor skills, to respond without writing or typing, which were barriers to his ability to express what he had learned. Alice liked to choose to video record herself responding to the bell ringer. All students had these options that addressed their strengths, preferences, and helped the teacher gain a clearer picture of students’ understanding of the content without the barriers that may have prevented some of them from expressing all they know.

Ways that instruction is provided in classrooms often presents barriers to student learning. Whole group instruction can be difficult to follow, and the pacing may be too fast. Directions are often multi-step and presented verbally. Mr. Londeree and the teachers discussed early in the year all of the possible barriers that instruction might present to the class and made a list. After developing that list, they examined it again in terms of any additional barriers that might be in place for Alice and Matt. Considering UDL, the teachers decided that lessons would be taught in station rotations to allow for the needs of students to be addressed in smaller groups. Stations and materials for classes were color-coded with labels for reference to assist students with visual schedules of the rotations. Color-coded materials also supported Alice and Matt in identifying what materials in their lockers they needed for each class (e.g. math materials were red, ELA materials were blue). Multi-step directions were video and audio recorded for students and shared on the LMS for students to view as many times as needed. Mr. Londeree recorded small group lessons for Alice and Matt to highlight the big ideas in the lessons for them. These videos were available in itslearning to all students who needed to hear the big ideas of the lesson again; they could be accessed at any time, including at home. Implementing these different tools that assisted Matt and Alice to get information...
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benefited all students and were available in the environment for daily use for everyone.

In the early months of school during social studies, all Mavericks began working on projects on specific bodies of water in the United States. Mr. Londeree and the social studies teacher designed multiple options for students to choose to complete the project and show what they learned. Students could choose to create a 5-slide Google Slides, complete a one page paper, record a five-minute presentation, or create a poster. Alice and Matt both chose to complete a 5-slide Google presentation and used the app, Speak It, to record the narration for their five slides. The slides and recordings highlighted the big ideas that Alice and Matt had learned about their topic and allowed them to focus on interacting and answering questions from other students during the presentations.

At the end of the first quarter of school, Alice and Matt were part of the classroom community with their peers. Removing barriers by providing multiple options of engaging in, presenting, and assessing content and learning have supported Alice and Matt to transition into the inclusive environment successfully. Teachers who used the UDL framework to design learning experiences that removed barriers created an inclusive setting in which Alice and Matt could participate and belong. Mr. Londeree worked closely with other teachers to make sure that options were available to Alice and Matt to get information, show what they learned, and engage them. Mr. Londeree and the other teachers on the Maverick team believed that their responsibility for serving students with significant disabilities was to create environments where the students develop independence and met appropriately challenging learning expectations.

Students in classrooms that have been intentionally designed with the UDL framework develop into motivated, resourceful, and strategic learners. Over time, students like Alice and Matt will become more motivated as they are given opportunities for autonomy in choice and goal-setting. They will learn to be resourceful when they face a problem in the classroom and will become strategic as they learn to meet short-term goals. Furthermore, having Alice and Matt in an inclusive setting also pushed students without disabilities to step outside their comfort zones and develop an appreciation of collaborating with a broad spectrum of learners that included Matt and Alice.

While using UDL as a framework to design the learning environments for Alice and Matt, teachers at Central Middle School in turn designed environments that benefited a wide variability of learners. The teachers in this district have been implementing UDL guidelines to reduce barriers and design inclusive environments to accommodate diverse learners for a number of years, but how can you begin tomorrow with this way of designing learning in your classroom? Implementing UDL effectively is a process that takes time as a practitioner learns and applies the principles of the framework, but as every journey of a thousand miles begins with one step, UDL implementation begins with a plan.

A Plan for Next Steps to Implement UDL

Beginning the process of using the UDL framework might seem daunting, but approaching UDL with a purposeful and meaningful plan can make the process less daunting. Planning for all learners (PAL) is a 4-step process developed to guide teachers in implementing the UDL guidelines (Meo, 2008). These steps are:

1. Set goals that align with skill development or content. Goals should not include a specific means to dictate how students will express their learning.

2. Determine what methods, materials, tools, and assessments will be used for instruction and application. Once these are determined, identify barriers that could exist for the learner variability in a classroom.

3. Apply the UDL guidelines to remove barriers and add support/scaffolding to materials, methods, and assessments. Does the plan consider multiple ways to engage all students? Does the design include multiple ways of representing ideas and information? Does the design include multiple means of supporting students’ expression of their learning?
Universal Design for Learning: Attaining Meaningful Access for All

4. Teach the lesson and reflect on the success of students. What barriers were not considered? Can they be removed in the future or does scaffolding need to be included? Revise the next lesson and repeat the process. Specifically consider that students with significant disabilities may need additional supports/goals added into the learning environment.

Practitioners can immediately begin changing or enhancing their practice by using the UDL framework. Find resources to support UDL implementation and other practitioners who will share your commitment to designing for all students. Reflect on intentionality in planning, identifying barriers, and begin your UDL journey. Teachers who implement UDL can attest that it is a process that is continual, both because learners change and materials that become available change over time. However, what will not change is the need for practitioners who understand the imperative for equitable learning by implementing universal design for learning in today’s classrooms.

References


Introduction

Discussions around large-scale assessments often focus on the test as being an instrument of good or, more often, ill. Test developers, state and local administrators, and teachers routinely question the validity and usefulness of test scores for their students. Such questioning is good practice and, when considering academic achievement tests, it is crucial to question the validity and usefulness of test scores in relation to the assessment system as a whole. When discussing assessment “alignment” (i.e., the degree to which the test questions represent the academic content standards), educators and parents should consider that alignment goes beyond matching test questions to standards and includes connections across various aspects within and across a system (Forte, 2013a, 2013b). The real alignment question is: “To what extent has the assessment and its operational system been designed to yield scores that reflect students’ knowledge and skills in relation to the academic expectations defined in the standards, and how well has this design been implemented?” (Forte, 2017, p. 3). In other words, assessment and instruction together as a system should provide educators and parents with an accurate picture of what students know and can do, so that they clearly see students’ progress towards achieving academic content standards. When alignment is understood in this way, the need to examine instructional systems and practices with the same rigor as we do assessment systems becomes an intrinsic part of any classroom-, school-, district-, or state-level reform effort. These systems must be aligned with each other and with the goals and expectations of all stakeholders to be effective and serve their intended purposes.

With the recent shift in science instruction spearheaded by the National Research Council’s (NRC) *A Framework for K-12 Science Education* (2012), discussions of science instruction and assessment seem timely. NRC’s framework introduces a more integrated and interdisciplinary approach to science instruction. Because this shift has “increased cognitive demands for all students, including [students with significant cognitive disabilities]” (Anderson & Nash, 2016, p. 19), the need to align science instruction and assessment for students with significant cognitive disabilities might pose new challenges for teachers, school leaders, districts, and states.

While education practitioners might recognize the importance of high-quality instruction to their students’ long-term success, they might struggle to seamlessly align assessment with instruction. Alignment with instruction is important for any assessment, but particularly so for large-scale alternate assessments based on alternate achievement standards (AA-AAS) for students.
with significant cognitive disabilities. Because of their learning characteristics, they need ongoing support to maintain and generalize skills. Therefore, the best way to assess their learning is often to have assessments embedded within daily instruction. To ensure long-term student success, practitioners who work with students with significant cognitive disabilities should consider every stage of learning and instruction – from the development and implementation of an Individualized Education Plan (IEP), to the administration of standardized assessments, to the interpretation of scores – together as a cohesive system (Kingston & Broaddus, 2017; Black, Wilson, & Yao, 2011). Included in these stages is the enacted curriculum (i.e., what and how of instruction) that addresses the intended curriculum (i.e., the state academic standards).

**Instruction as Part of the Assessment System**

The need for coherence within instructional and assessment systems is vital to the success of science education but can be challenging to achieve given the need for consistency across systems at multiple levels (i.e., state, district, school, classroom; NRC, 2012). To achieve coherence, there should be a common understanding among stakeholders at every level of (a) the “goals for science education (and for the curriculum) that underlie the standards” and (b) the “purposes and uses of assessment” (NRC, 2012, pp. 245-246).

A Theory of Action (ToA) helps ensure an aligned and valid assessment system by illustrating the components of the entire system, including instruction, and how they interact together (Perie & Forte, 2011). Two components from edCount’s ToA approach that are critical for a coherent and valid assessment system are illustrated in Table 1. Examples of claims for these components are shown in Table 1. Each of these claims provides an opportunity to not only assess quality and alignment to state academic standards and expectations, but also to investigate where barriers to students’ opportunity to learn and demonstrate their progress might exist.

**Table 1. Claims for Instructional Content and Delivery and System Goals**

<table>
<thead>
<tr>
<th>Component</th>
<th>Claims</th>
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<tbody>
<tr>
<td><strong>Instructional Content and Delivery</strong></td>
<td>Expectations for college and career readiness are clearly defined.</td>
</tr>
<tr>
<td></td>
<td>Teachers have the knowledge and orientation necessary to provide high quality academic instruction.</td>
</tr>
<tr>
<td></td>
<td>Administrators have and apply resources to support effective school and classroom functioning.</td>
</tr>
<tr>
<td></td>
<td>Teachers have resources and supports necessary to deliver instruction.</td>
</tr>
<tr>
<td></td>
<td>Teachers provide instruction aligned with grade-level content.</td>
</tr>
<tr>
<td><strong>System Goals</strong></td>
<td>All students get greater exposure to high quality academic instruction.</td>
</tr>
<tr>
<td></td>
<td>All students achieve increasingly higher academic outcomes.</td>
</tr>
<tr>
<td></td>
<td>All students leave high school ready for college and careers.</td>
</tr>
</tbody>
</table>
Articles from Our Contributors

Promoting Opportunity to Learn: Rationale and Resources for Science Instruction

Current State of Science Instruction
The definition of high-quality science education has changed as we have moved into the 21st century, as teachers are tasked with “providing the foundational knowledge for those who will become the scientists, engineers, technologists, and technicians of the future” (NRC, 2012, p. 12). Therefore, science instruction as currently taught and assessed must change. “It is essential that all students have access to a high-quality science education that provides them with the skills and knowledge they need to be well-informed citizens, to be prepared for college and careers, and to understand and appreciate the scientific enterprise” (NSTA, 2016, p. 1).

The recent shift in science instruction and assessment has brought to the forefront the idea that students should build continually upon previously acquired knowledge and skills, and that an understanding of science (and engineering) requires integration of different sets of knowledge and skills (i.e., dimensions of learning). These concepts are outlined in *A Framework for K-12 Science Education* (NRC, 2012), which provides a guide for standards development, curriculum design, science education, and professional development. A key component of the framework is the three-dimensional approach to science education: Scientific and Engineering Practices, Crosscutting Concepts, and Disciplinary Core Ideas (see Table 2).

Table 2. Three Dimensions of Science Education

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>The ways scientists and engineers work when investigating, developing theories, designing, and building models and systems.</td>
<td>Concepts across all disciplines of science (e.g., life, physical, and Earth/space).</td>
<td>The conceptual framework that students can build and expand upon when presented with additional scientific content, starting in kindergarten and continuing through the end of high school. Research supports this approach of building concepts over a period of years (Michaels, Shouse, &amp; Schweingruber, 2008).</td>
</tr>
<tr>
<td>Guidance for educators in having students move beyond isolated facts by engaging in the practices in the classroom.</td>
<td>Bridge to help students connect the knowledge, skills, and concepts between that they have learned in one science discipline (e.g., patterns of a life cycle in life science) to something learned in another science discipline (e.g., patterns of Earth’s orbit around the sun in Earth and space science).</td>
<td>Four domains included: physical sciences, life sciences, Earth and space sciences, and engineering, technology, and applications of science.</td>
</tr>
<tr>
<td>Practices such as asking questions (for science) and defining problems (for engineering), developing and using models, and planning and carrying out investigations.</td>
<td>Concepts such as patterns, cause and effect, and scale, proportion, and quantity.</td>
<td></td>
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</tbody>
</table>

While *A Framework for K-12 Science Education* acknowledges that there is no single “right” way to integrate the three dimensions within instruction and assessment, it does emphasize that alignment with the conceptual ideas of this framework requires that the three dimensions be taught and assessed together – one cannot be isolated from the others (NRC, 2012). Joe Krajcik explained, “You cannot learn the ideas of science in isolation from the doing and you cannot learn the practices of science in isolation from the content of science” (Krajcik, para. 3, 2016).

This shift affords students with significant cognitive disabilities who may not have previously received science instruction the opportunity to engage with scientific content in a meaningful way. The focus on crosscutting concepts, which prompt students to build on previous knowledge and skills and integrate different sets of knowledge and skills, benefits students with significant cognitive disabilities by providing them the opportunity to practice maintaining and generalizing those knowledge and skills.

In addition, the focus on the scientific and engineering practices, which involve problem solving, goal setting, and monitoring, support students in developing important self-determination skills.
Potential Barriers to Students’ Opportunity to Learn

Despite the initiatives taken by states, districts, and schools in response to the requirements and recommendations set forth in federal policy (IDEA, 2004; ESSA, 2015), barriers to science education for students with significant cognitive disabilities persist. These include:

1. The lack of preparedness (e.g., preservice training and professional development) of general education science teachers in working with students with disabilities (McGinnis & Stefanich, 2007; Kahn & Lewis, 2014); and
2. The limited knowledge in science content of elementary school teachers and special education teachers to provide science instruction to students with disabilities (Scruggs, Mastropieri, & McDuffie, 2007).

The National Science Teachers Association (NSTA) cites additional barriers to science education for this student population, including “inadequate equipment, communication difficulties, insufficient numbers of instructional assistants and tools in the classroom, and lack of overall administrative support” (NSTA, 2017, p. 1).

However, recent research has provided evidence that students with significant cognitive disabilities can acquire science knowledge, skills, and concepts. Students with significant cognitive disabilities have used science inquiry to acquire science content (Browder et al., 2010; Miller, Krockover, & Doughty, 2013; Miller & Taber-Doughty, 2014); acquired and maintained STEM skills (specifically mathematics) using embedded simultaneous prompting procedures in inclusive settings (Heinrich et al., 2016); and acquired science vocabulary and concept knowledge while fully participating in science activities and utilizing a KWHL chart (i.e., what do you Know?; What do you want to know; How will you find out?; what did you Learn?; Jimenez et al., 2012). Some of the same research indicated that instruction and progress occurred within the general education classroom (Heinrich et al., 2016; Jimenez et al., 2012).

Supports for Educators

To reduce potential barriers to accessing the three dimensions of science education (i.e., Science and Engineering Practices, Crosscutting Concepts, and Disciplinary Core ideas) for students with significant cognitive disabilities, edCount has worked with state departments of education to provide instructional resources and supports in science for both special and general educators. Resources and supports for administrators and teachers are crucial to achieve coherence throughout the various system components – specifically, within and across the Instructional Content and Delivery and System Goals components – as described above (see Table 1).

Interpretation of Standards

Collaboration with the states has led edCount to determine key aspects included in each state science academic content standard and to create related knowledge, skills, and abilities statements to define instructional content for students with significant cognitive disabilities. While the complexity of the statements may have changed from the original science standards, they remained aligned with grade-level topics and academic content. In addition, a concept that serves as an entry level into the standard was provided for each standard to provide an “entry” point for students who have a less sophisticated understanding of the concept. The entry level statement should support, not replace, instruction on the related knowledge, skills, and abilities statements. These statements promote overall system coherence and validity by supporting the claims of the Instructional Content and Delivery component (e.g., “Expectations for college and career readiness are clearly defined”) of the ToA (see Table 1).

An example in which the key aspects of a grade 5 standard are determined and the related knowledge, skills, and abilities statements and an entry level are created is illustrated in Table 3. These statements support educators by providing information that allows for varying degrees of student understanding and provide accessibility to a full range of students with varying characteristics.
### Table 3: Example Grade 5 Standard

<table>
<thead>
<tr>
<th>Three Dimensions</th>
<th>Science Academic Standard</th>
<th>Knowledge, Skills, and Abilities Statements</th>
<th>Entry Level into the Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disciplinary Core Ideas</strong></td>
<td>5-PS1-2. Measure and graph quantities to provide evidence that regardless of the type of change that occurs when heating, cooling, or mixing substances, the total weight of matter is conserved (NGSS, 2013).</td>
<td>Recognize that the total weight of matter is conserved by comparing the weight of an object before and after it changes from a liquid to a solid or from a solid to a liquid. Recognize that the total weight of matter is conserved by comparing the total weight of the substances before and after they are mixed.</td>
<td>Recognize the change in state from liquid to solid or from solid to liquid of the same material.</td>
</tr>
<tr>
<td><strong>Science Practices</strong></td>
<td>Using Mathematics and Computational Thinking: With guidance and support from peers and adults, measure the given quantities using standard units to calculate the difference between the total weight of the substances before and after they are heated, cooled, and/or mixed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Crosscutting Concepts</strong></td>
<td>Scale, Proportion, and Quantity: With guidance and support from peers and adults, use measurements and calculations to describe that the total weights of the substances did not change after they are heated, cooled, and/or mixed.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Science Content Modules

edCount developed science content modules for science instruction to support educators in addressing the potential barriers for students with significant cognitive disabilities. The modules not only support educators’ knowledge of grade-appropriate science concepts, but also help to facilitate effective planning or modification of existing science instructional units (see Figure 1). The content modules provide educators with resources and instructional ideas to support the claims of the *Instructional Content and Delivery* component (e.g., “Teachers have resources and supports necessary to deliver instruction”) and the *System Goals* component (e.g., “All students get greater exposure to high quality academic instruction”) of the ToA (see Table 1).

### Science Practices and Disciplinary Core Ideas

The modules support an approach to science instruction that incorporates science practices while instructing the Disciplinary Core Ideas, and they decrease the emphasis on the practice of rote memorization of facts for all students, including students with significant cognitive disabilities. To help educators plan for instructional units, the modules provide...
examples for each science practice, along with links to additional online resources related to the science practices and module topic. Examples in the domain of life science for the practices *asking questions* (for science) and *defining problems* (for engineering) are: How are plant and animal cells different? How does the heart and lungs work together? How are you able to smell perfume or a strong smell?

In addition, each module provides a high-level list of key information covered by the standards. The lists provide educators a quick glance at information to include when planning each instructional unit. Also included are links to online resources that educators can visit to gather information on the topic as needed.

**Module-specific content and crosscutting concepts.**
The modules provide concepts specific to the module topics and serve as a strong foundation of understanding and supporting the students in learning new concepts across science domains and grades. Some concepts may apply across multiple content areas and instructional emphases (e.g., cause and effect in reading science texts). The concepts correspond to the Crosscutting Concepts in *A Framework for K-12 Science Education* (NRC, 2012) (e.g., patterns, systems and systems models, structure and function). Following are examples across different domains of the concept that patterns can be used to determine similarities and differences:

1. Life science: in life cycles of different organisms.
2. Earth and space science: in daily changes in the direction of shadows.
3. Physical science: to classify different kinds of materials by their observable properties.

**Vocabulary and background knowledge.**
Another support included in the content modules is vocabulary, which is crucial to understanding science concepts. The vocabulary words that students gain through experiences provide ways for them to comprehend new information (Sprenger, 2013). Academic-oriented experiences and varied types of teaching vocabulary terms increases students’ ability to create background knowledge (Marzano, 2004). The modules address general vocabulary words: words that generalize to a variety of animals, plants, organisms, and activities. These general vocabulary words provide background knowledge that helps students make connections to specific content words (i.e., words associated with an organism, system, process, or phenomena). For example, the specific content word magnet connects to general vocabulary words of force, motion, and metal. Figure 2 illustrates the use of a graphic organizer to build an understanding of the term magnet. Students can test objects to determine which ones the magnet attract, and then sort the objects onto the graphic organizer (TDOE, 2016).

**Universal Design for Learning (UDL).** In addition, the modules include information on Universal Design for Learning (UDL), which is key for reaching the widest range of learners possible. The modules provide strategies and possible examples in each of the three UDL principles: Multiple Means of Representation, Multiple Means of Action and Expression, and Multiple Means of Engagement. Further, while the provided examples are for all students and attempt to reach the widest range of learners possible, codes are included to alert teachers to examples of activities that are accessible for students with a visual impairment (V), a hearing impairment (H), and/or a physical disability (P). Table 4 shows an example of the information provided in the UDL section (TDOE, 2016).

**Figure 2. Vocabulary example.**
**Promoting Opportunity to Learn: Rationale and Resources for Science Instruction**

### Table 4. UDL Example

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use assistive technology to allow students to interact with the instructional materials and content.</td>
<td>Have students interact with an online simulation that can be controlled with a mouse (e.g., <a href="http://www.scholastic.com/play/flash/gamejunk.swf">http://www.scholastic.com/play/flash/gamejunk.swf</a>). Use an adapted mouse.</td>
</tr>
<tr>
<td></td>
<td>Provide a USB microscope.</td>
</tr>
</tbody>
</table>

**Transference and generalization of concepts, knowledge, and skills.** To make learning meaningful for all students, including students with significant cognitive disabilities, the modules provide transfer and generalization ideas to help instruction intentionally make connections to future content, real-world application, and college and career readiness skills. They also provide examples for using science instruction as the catalyst for development in other areas, such as communication skills, reading/listening comprehension, mathematical skills, age-appropriate social skills, independent work behaviors, and skills in accessing support systems.

**Tactile maps and graphs.** The final set of supports included in the modules are guidelines for creating tactile versions of maps diagrams, models, and timelines for students who are blind or deaf-blind. However, the tactile versions might be beneficial to other students as well. The modules provide links to online resources for additional information, ideas, and examples to support educators in implementing this support for their students.

### Conclusion

While the recent evolution of science instruction and assessment to ensure that all students are well-informed citizens and are better prepared for college and careers can present challenges to education practitioners, particularly those who work with students with significant cognitive disabilities, increased science knowledge and the provisions and use of appropriate resources and supports can help significantly in achieving quality, alignment, and coherence throughout entire instructional and assessment systems.

Specifically, resources that align with federal and state expectations (e.g., grade-level and content-specific standards), current research, and best practice – but also reflect the specific and immediate needs of teachers and students – are vital to ensuring alignment between instruction and assessment. edCount has created materials for schools, districts, and states to bridge the gap between classroom instruction and the evolving national instructional and assessment landscape intended to strengthen science learning. The online-accessible resources that edCount develops (such as the modules described in this article) promote:

1. ongoing support for teachers and administrators to implement reforms in their classrooms and schools;
2. a common understanding among all stakeholders of goals and expectations;
3. high academic expectations for all students;
4. the use of evidence-based techniques and strategies for achieving goals and expectations; and
5. accessibility to grade-level academic content for all students.

The proper tools and resources, developed with both classroom-level and larger-scale needs in mind, can promote system coherence (and thus, overall quality and effectiveness) by increasing the validity of the Instructional Content and Delivery and System Goals component claims stated in the ToA (see Table 1). The implementation of well-designed instructional supports can help practitioners who have a range of science knowledge and experience understand the large- and small-scale goals of science instruction for all students. A common understanding among practitioners of these goals, along with the right instructional supports, can help to transform the achievement and experiences of students with significant cognitive disabilities in science and beyond.
Articles from Our Contributors

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References


I think in colors. My thinking colors have sound and movement. When I hear spoken words my neurology automatically goes for the match – a match for the words I hear to a familiar concrete picture of something in the world outside my skin or to an internal picture I have stored in my memory.

When I was a girl I heard the saying, “I got the world by the tail.” Immediately, the matching pictures of my experience of the world popped up for me to see. I found the best match and promptly assigned the words, “I got the world by the tail” to mean the interaction of the sunlight and misty water particles I could see rising up from the earth’s surface whenever I was outside.

The phenomenon of mist rising from the earth became the visual match for the new words I imagined to be about the world’s tail. For most of my life I thought this literally was this early morning mist was indeed the earth’s tail. I thought that people were somehow able to physically grab onto this tail and when they did so they indeed had the world by the tail! To my literalness this made perfect logical sense.

I had always noticed the sun sparkles and the interaction of the sun sparkles with the earth mist. In fact, as a small child, they were often more salient to me than the people in my world. Most times I preferred them to people. I had often tried to touch these sparkles, but now I had a new mission. I wanted to actually catch this tail so I too might have the world by its tail! As a decades older person, a few years ago I used acrylic paints to paint some of these misty tails. Here is one example with many more at my website, www.judyendow.com

**Figure 1. Earth Tail Mist**

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Autistic Visual Thinking Impacts Comprehension

Points to Ponder

Rote Repetition is NOT Evidence of Comprehension!

People with autism are often visual thinkers. It is not something we decide, but rather the way our brain handles information. We do not know when we are little that most other people think with words rather than with colors and pictures. This makes it difficult in school as delivery of information quickly becomes language-based as pictures drop away after the first few years.

This dramatic change in materials in the United States occurs at the third grade level when text based instruction becomes predominant. For me it was hard to think about or understand ideas that were not concrete ideas. Basically, if my brain could not translate the words I heard into a concrete picture in a few seconds, as a young child I would not be able to pick up the meaning of the words being spoken. Even though I did not understand the meaning I was able to repeat the words. For example, when prompted I could repeat the teacher’s instruction to use quiet voices even though I had no idea what the words meant because no picture popped up in my head to equal those words.

Is your youngster a visual thinker?

Do you use concrete language along with pictures as needed?

Non-compliance or Comprehension Constraint?

When autistics are able to recite your instructions or repeat an admonition and then do not follow the instruction or admonition do not assume willful non-compliance. Instead, check for comprehension. If the autistic is a visual thinker ask him to draw or show you what the instructions or rule looks like. If a visual thinker cannot do this, he likely does not comprehend the words you are speaking even though he may be able to repeat them quite accurately. Children with ASD have been shown to perform basically normal for age in word decoding, but lower than age expectation in reading comprehension. (Minshew et al, 1994; Myles et al, 2002; Nation et al, 2006; Newman et al, 2007; Asberg et al, 2008; Asberg et al, 2010)

When your student’s behavior has the appearance of willful noncompliance do you stop to ascertain comprehension before ascribing meaning to the behavior?

How will you evaluate your student’s comprehension or lack of comprehension when his behavior looks like non-compliance?

Teach Idioms and Other Hidden Curriculum

People with autism don’t automatically pick up the meaning of idioms. However, they are able to learn the meanings of idioms by direct teaching. “I’ve got the world by the tail” is an example of an idiom. Sometimes an autistic will automatically assign a literal meaning to an idiom and then assume everybody else shares that literal meaning because it makes sense to him! That is what I did in the above example using the idiom “I’ve got the world by the tail.”

How will you teach the meanings of idioms and other kinds of assumed social understanding, i.e. hidden curriculum?

Do you check for shared meaning when it comes to idiom usage and understanding?

References


The Right to Opportunity to Learn
By Amanda Raymond, Parent

When one thinks of school, many images come to mind: loud, boisterous chatter as students make their ways through crowded halls, classrooms full of engaged learners intently listening to the instruction or paging through a book looking for answers, rich laughter during a game of tag at recess, or even parents hugging and kissing their kids as they are dropping off or picking up. Being a military brat, spouse and service member, I have seen my fair share of schools in various neighborhoods, cities and states. I’ve seen parents and kids of all sizes, shapes, colors, races, ethnic and socioeconomic backgrounds, and even abilities. We are all different, and yet, we have so much in common. We want to see our kids learning and engaging as they discover new things at school. We want to see them have help and understanding when they struggle. We want to see them have friends and to feel like they belong. Most importantly, we want our children to be independent, successful and employed as they grow into adulthood. These are all the things that each person needs to live a full, meaningful life, and that is why I feel inclusive classrooms are so important.

As infants, we start learning by observing what happens in the world around us and by taking in all the sights and sounds; but we never really know what a child retains, we just know they soak up as much as their tiny brains will hold. Both of my children have autism, but my son is impacted more significantly, with limited language and those classic symptoms associated with autism. For some reason, when we find out our child has a disability, we feel devastation, albeit justified, but we also start doubting our child’s capabilities and their potential. From those first moments as parents, as with any child, we wouldn't give up or think our children can’t learn. It should not be any different for our children with disabilities. Our kids just learn a little differently. Instead, we have to change the way we think, adapt to differences and think creatively with our approach to every aspect of our lives. Personally, I never really looked at my children as having a disability. I knew they had differences, just like any other child. I knew they had strengths and weakness, and we approached them just like any other parent. I don’t feel like I experienced true anxiety about my son’s future until I realized three things: (1) the severity of my son’s deficits were extensive and significant; (2) the idea that he would attend school in a district that excluded and segregated; and (3) ultimately, on a broad scope, that our community was not prepared or educated to accept, welcome and accommodate him.

Why Inclusion?
To start breaking down the reasons why inclusive classrooms are so important, I would put at the top of my list the fact that it is a civil right. Every student is afforded the right to a free and appropriate public education and yet, students with disabilities are often segregated to multi-age, self-contained classrooms, away from their non-disabled peers with watered down curriculum, which is often not age appropriate and far below grade level. The model our current school district follows places students with disabilities into classrooms based on their disability category. Both my children had limited time in the least restrictive environment simply because of their disability, simply because they had more support needs. This is especially true for my son, who was placed...
in a regional program when we moved to our current home. His autism significantly affects his ability to communicate with us and it interferes with his ability to demonstrate the knowledge he possesses. When students aren't able to verbally express or demonstrate their knowledge, or when their disabilities get in the way of communication, it is often assumed they cannot or do not understand. In my opinion, it is one of the biggest misconceptions and causes the most detriment. My son is now 10 and it has taken me years to realize this; I now realize he understands more than he is able to tell me. It has also taken a long time for me to admit that I have been doing him an injustice by assuming otherwise. Without the ability to communicate, we often don't know what our kids are capable of learning, but it doesn't mean we give up. We cannot deny the opportunity to learn that is so rightfully theirs.

Adapting materials and providing choices can make grade-level, meaningful and enriching content accessible at any level, affording our students with disabilities the opportunity to learn the same things as their peers. Academic curriculum is designed to prepare students systematically for the next step. The next step might be the next grade, then to middle and high school, vocational school, or college, and then employment, a place in the community, and relationships with family and friends. This is how we prepare any student for life. Students’ interests are explored and expanded, as new and exciting curriculum is introduced grade after grade, allowing students to find their talents and their passions as they learn and grow. This process allows students to choose their path; a choice that is routinely denied to our students with disabilities, and especially to those with extensive support needs. I want what any parent wants for their child. I want to see him have a full, happy, meaningful life in whatever way he chooses, with whomever he chooses, that is as independent as possible. If we hope to accomplish that, our students with disabilities should be exposed to the same content and material as their peers.

To achieve a level of independence that we expect of our children as they grow, graduate from high school, pursue post-secondary education and eventual employment, students are challenged to engage in a multitude of creative ways, from foreign language, financial literacy and dramatic arts to engineering, technology and software programming. When students get to middle school and then high school, their world opens to a plethora of choices. However, students with disabilities, especially those who have been educated primarily in self-contained classrooms, have not been prepared for the academic rigor and the high expectations required to achieve a standard diploma. Because of a rigid curriculum and a pacing guide that is used to prepare students for state standardized tests, it is believed that to accommodate our students with disabilities, they need to be relegated to a separate environment. It is believed this separate environment is not only needed, but also the best choice to provide the “specialized instruction” that is required by law for students with disabilities. These old school attitudes and beliefs hinder real effectiveness and are a huge barrier to successful learning. More so, they create a prejudice against students with disabilities inhibiting the educational process. There are so many opportunities that our students miss when they are not included with their peers.

Broading the Scope of Inclusion

Including our students with their typical peers, not only in the general education setting, but also in the school community, would help prepare them for life in the real world. It exposes them to the fluidity of our environments, teaches them to recognize their needs and self-advocate, and shows each student they are capable of more. The potential is limitless if we support, encourage and believe in our students. We raise our children with the ultimate goal of being as independent as possible, in whatever capacity that may be. That end result may look different for each child, but each of them deserves the opportunity to reach that goal. Both of my children have very different needs and what their eventual levels of independence will look like may be very
different. But it is my job as a parent to try everything and to give them every opportunity that is given to any other typical child. I think as parents, we don’t like to see our child struggle and we hate to see them hurt; for parents of children with disabilities this is tenfold. We have more factors to consider, more needs to address, and more battles to fight. We know that when our kids fall, they fall harder. There are greater implications to their social, emotional and physical well-being as we help to pick themselves up.

The Impact of Segregation

The Autistic Self-Advocacy Network states that how children are treated in schools today often mirror how they are treated later in life. I want my children to live in a community that accepts them, a community that is compassionate and understanding, and it all starts at school. It starts with their teachers and their peers. Reciprocal relationships, however, are often elusive to our students with disabilities. Many of our students struggle with typical social interactions simply because of their disability; this coupled with a segregated class society creates even bigger obstacles. In a culture of self-contained classrooms, they are not only denied the same opportunities to learn, but they are also separated from peers with whom they might have otherwise formed a connection. The American Journal of Sociology published a study on how high school students choose their friends and surprisingly, it wasn’t based on what we might have thought … students don’t choose their friends based on those typical categories like nerds, jocks or band geeks (Frank, as cited in Wood, 2015). The study found that most friendships were formed when students took the same sets of classes and they were more likely to make friends with students in a core class or an elective than in a large physical education class, where students with disabilities are often allowed. The professor in charge of the study also shared that schools who do not proportionately balance their classes with students with and without disabilities, but homogeneously group based on ability, run the risk of driving students apart both socially and academically.

This segregation has a disastrous effect on students with disabilities’ self-concept and self-esteem, causing further withdrawal. Through the segregation of classrooms, we send the message that students of certain abilities do not belong because they “can’t keep up” with the pace or “don’t have the cognitive ability to understand” the content. Academically, our students’ weaknesses are amplified in a general education classroom when they cannot independently access the content and material presented. They often sit in isolation, too nervous to ask for help and draw attention to their deficit. My daughter often shares that she feels stupid or doesn’t think she can do what the other kids do, simply because she has a disability. Her deficits in reading and comprehension limit her from truly accessing the content and she struggles to understand the instruction provided. If you think of visiting a foreign country, it is a hard place to be when you cannot understand the language. Without the necessary modifications, accommodations or support, being in a general education classroom can feel just like a foreign country. Socially, she struggled to connect with peers because she was only with them for part of the day or only during certain subjects. Past negative experiences have embedded this fear of rejection that hinders any future attempts to connect. She compensates by creating friendships with her dolls, fooling herself into believing that she doesn’t need or want friends, and is in fact happy without them. Thus, because of social and academic voids, school becomes a place where she doesn’t want to be. This is not what I wanted for my child.

One would think it would be easier to include students with less support needs or minimal maladaptive behaviors. As kids get older, they garner more skills, allowing them to be more meaningfully included. There was a time, early in elementary school, where my daughter was included. She had a smile on her face, she was more persistent in her efforts, and could relate to (and commiserate with) her friends because they all took the same test or completed the same project. Yes, she had the same opportunities as her nondisabled peers. That was a time when she wanted to learn, when she wanted to go to school. After we moved to our current home in fifth grade, that sentiment changed. Because of her disability, she was placed in self-contained classrooms. Although there were plenty of adult support and specialized instruction, the message she heard was, “You’re not good enough,” and, “You can’t do it.” With no way to make meaningful connections, she doesn’t have friends; faced with low expectations and inaccessible content, she doesn’t enjoy learning. In her words, she hates school. The only sentiment she shares now is she wants to be free of it all. She says she doesn’t feel like she belongs anywhere. As a parent, I’ve seen the drastic and dreadful change in her as a student and as a person from an inclusive environment to a segregated one. It was that shift that made me question everything I had previously known and spurred me to learn more. For her sake, and for my son’s, I needed to find a way to help them be happy. For most of us, happiness is belonging; isn’t that what all parents want for our kids?
Similarly, the same division occurs at the elementary levels, where students with significant deficits or support needs are relegated to participate in only noncore academic classes or enrichment classes like art, music or physical education. Worse than that, students with extensive support needs often have no access to their non-disabled peers at all. Those coveted reciprocal relationships never develop because although most kids are unconditionally kind, most kids are also inherently afraid of the unknown; they are hesitant to approach a student who is different. At those young ages, most kids can be naturally welcoming; when given an explanation, the differences aren’t as big as we think. They realize the differences aren’t all that different. All kids like to have fun and play with others; many love to play outside, running, jumping, climbing, swinging and sliding. My son doesn’t typically initiate interaction with peers, but he loves to play with them; he loves to watch them having fun and gets really excited to be around them in large groups. It is during games like tag or basketball where we see independent, spontaneous attempts to communicate, sometimes it’s one word or phrase like, “tag, you’re it” or “my turn.” Every child deserves to experience this kind of joy. As a human being, it’s these moments that we remember most. We can’t contrive these moments; they occur naturally.

In self-contained classrooms, there are also missed opportunities for peer support. Most of the kids in my son’s classroom are non-verbal, challenged by sensory and environmental stimuli, and often need a lot of facilitation and prompting to participate. Opportunities for interactions that naturally occur almost never happen in this setting. When kids of all abilities are together, there are countless opportunities for peers to work together; it could be in the lunchroom, in pairs, or in a small group. We don’t usually think of this kind of interaction as collaboration or an opportunity to socialize, but problem solving and working together is just that: socialization. It could be as simple as my son turning to a peer at lunch to ask for help opening his chip container, which wouldn’t have occurred if the assistant had sat between him and his classmate at the lunch table that day. It could be as complex as using his talker to help present a group project in the classroom, which would take some creative thinking but could allow for peer support. It could be as spontaneous as seeing a group of kids on the playground blowing dandelion fluffs and running over to pick one and blow on a fluff too; the moment so fleeting, you would miss it if you blinked or weren’t looking in that direction. But that is socialization and it is amazing to witness. I can assure you that it happens when my son has had the same opportunities as his peers; so even though he is different, he deserves the opportunity to learn. These opportunities lead to full, independent futures, which depend on our ability to recognize each other’s strengths and figure out ways each of us can contribute to the greater good.

The Right to Opportunity to Learn
I know my son, and other students like him, learn differently; I know they need more support. They also have a right to be academically challenged as much as any other student. I recently asked for the class schedule that has become my son’s routine and then I added up the amount of instructional time within that classroom’s schedule. Direct instruction is 15 percent of his day; group instruction is 41 percent. Although my son is not proficient at grade level, I believe he could still receive the majority of his instruction in the general education setting with modifications, accommodations and support. It would expose him to the same interesting and engaging content as his peers, because I do not want to underestimate his ability to understand. It would also allow him to interact with his typical peers, have models for language, communication and socialization, and to learn the expectations of a typical student, right down to quieter voices in the classroom and how we walk safely in the hallway. It would help him to adapt to and tolerate the sensory stimuli found in classroom environments, from lights and noise to the number of people within a confined space. With the opportunity to make choices, it would allow him to start recognizing his needs and self-advocate when he needed a break from that environment. This type of basic behavior is often overlooked, but is key to the beginnings of an independent future.

As parents, we often ask ourselves questions about our child’s future and what we want for them as they grow and become adults. For parents of children with disabilities, those questions are often harder to answer. How will my child live when I am gone? What will his or her daily routine look like? Who will help him or her dress, or eat or have basic needs met? How will he or she still enjoy the things they love to do? Sometimes it’s as simple as finding a little support and guidance to manage money or get to work on time, but sometimes it’s harder than that and we worry about long term care for more significant support. Some kids with disabilities have siblings or extended families to aid in finding that solution. My family doesn’t have that luxury; my children don’t have family to care for them after we are gone and there is definitely no one living within the same area. Perhaps this is why the benefits of inclusion are more apparent to me than
The Right to Opportunity to Learn

some. Maybe this is why I recognize that my child has a right to learn what every other child has the opportunity to learn. Schools are definitely a place to learn academics, but they are also the place to learn about life.

Giving children with disabilities these opportunities to learn in an inclusive environment not only promotes engaged learning and supports independent futures, but it also builds better communities. These opportunities to interact with one another create compassionate friends and understanding neighbors. To me, it is so exciting when a student from my son’s class sees us out walking in the neighborhood or riding bikes and they wave or yell hello, calling out his name as they pass by. It may seem mundane and trivial to some, even taken for granted, but it’s something that wouldn’t occur if he were not included in his class with typical peers. That feeling of belonging in a community cannot be duplicated and knowing that my son is accepted fills my heart with joy.

I went to a workshop in the fall that discussed financial planning for children with disabilities. The presenter had said that the two most traumatic events in a person with a disability’s life is when they lose their parents and when they lose their home, which usually go hand in hand, occurring simultaneously. Without these inclusive opportunities, without the ability to learn what every student has the opportunity to learn, I fear the worst. I fear my children will have no independent skills and no one to rely on when the time comes when I am no longer here to support them. I fear they will have no friends with whom to connect, enjoy or share life. I fear they will be alone and scared because there will be no one in their life who is familiar and comfortable, no one who understands their unique eccentricities. I fear that they will not be prepared for life in the real world.

The one thing I have learned over the years as raising two children with a disability is that the more exposure we can provide and the earlier we can start, the better my children will be able to navigate the nuances of life, from the mundane and trivial to the complex and complicated. It’s challenging. As a family, we have to plan and prepare to go out to community events and activities. There are a lot more considerations and preparations to manage, from noise and crowds to availability of bathrooms and snacks. Even barbecues and getting together with friends prove difficult because we can’t just sit back, socialize and leave our children unsupervised or unsupported. Facilitated play is left to us and the ability to participate may be short lived. For school, we communicate with teachers, offer ideas and assistance, volunteer for room mom or PTA, and then come home to play therapist, tutor and coach. It is exhausting and it is never easy. But we do it anyway. No matter which part of life, our children deserve the same opportunities that each and every one of us has. Regardless of ability or disability, our children deserve to see all that our world has to offer, to experience the joy and wonder of learning and doing, to learn independence and be satisfied with their own accomplishment. Their time in school is just the beginning and it ends with this thing we call life. It may not always look like what everyone else can do or how everyone else participates, but they still deserve the opportunity nonetheless.

References

Understanding, Identifying, and Effectively Responding to Trauma: Opening Opportunities to Heal, Grow, and Learn

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Introduction

Direct supporters often are left feeling confused and victimized in the face of seemingly unexplainable challenging behaviors. The term “challenging behaviors,” as we shall be using it refers to behaviors that do not meet the needs of the person to live a fulfilling life and are difficult to address through available supports.

Organizations such as the World Health Organization (WHO), Centers for Disease Control, American Academy of Pediatrics, and Harvard’s Developing Child Center have all identified the long-term effects of trauma on individuals and society. For individuals, trauma may result in “challenging behaviors,” an inability to focus, and absenteeism (Harris, 2014). When working with children who have experienced trauma, one of our primary considerations should be to do no further harm. Schools are beginning to adopt trauma-based interventions such as moving away from punishment-based consequences to more restorative justice types of supports. The after-effects of the experience of trauma are the main concern when examining the root of these challenging responses or adaptations to the trauma. While trauma is now a more common consideration for the neurotypical population, the same appreciation and application of trauma-based interventions are rarely considered for people who have overshadowing neurodiverse diagnoses such as autism or intellectual disability (IDD). While the neuro-processing differences are often blamed for challenging behaviors, we have found that the conventional unresponsive, controlling, structured approach to a trauma-based intervention for people with neurodiversity is much more likely to elicit challenging behaviors than the person’s neurological make-up alone.

Orchestrating an environment that promotes a strong sense of self and balance in the nervous system can both foster resilience in the face of trauma and promote healing. In fact, looking at the person’s day-to-day environment and augmenting it is a first step in offering supports. Finding therapeutic interventions is also important, but these interventions are relatively meaningless if the living environment is not supportive or exacerbates the problem through repetition of traumatic experiences or triggers.

In this article we will explore briefly the meaning of trauma, how it applies to supporting people with neurodiversity, as well as day-to-day approaches that can offer support and some promising therapeutic practices.

What is Trauma?

What is presented in this article applies to everyone. Trauma has been defined in similar ways by trauma experts over a span of time (Herman, 1992; Rothschild, 2000; Siegel, 2012; van der Kolk, 2014). The Adverse Childhood Experience (ACE) study gathered data from 1995 to 1997 about “abuse, neglect, and household challenges” for 17,337 children (Center for Disease Control and Prevention, CDC, 2016). The results revealed a stunning 69.9% of the children had experienced one or more events (CDC, 2016). A report written in California in 2003 stated that people with developmental disabilities have a 4 to 10 times greater chance of experiencing abuse and neglect then those without IDD (Protection & Advocacy, Inc., 2003).
Definition
The Center for Non-Violence and Social Justice (2014) offers the following definition of trauma:

The word ‘trauma’ is used to describe experiences or situations that are emotionally painful and distressing, and that overwhelm people’s ability to cope, leaving them powerless” (para. 1). Trauma has sometimes been defined in reference to circumstances that are outside the realm of normal human experience. Unfortunately, this definition doesn’t always hold true. For some groups of people, trauma can occur frequently and become part of the common human experience. In addition to terrifying events such as violence and assaults, we suggest that relatively more subtle and insidious forms of trauma—such as discrimination, racism, oppression, and poverty—are pervasive and, when experienced chronically, have a cumulative impact that fundamentally can be life altering. Particular forms of trauma, such as intentional violence and/or witnessing violence, sustained discrimination, poverty, and ensuing chaotic life conditions are directly related to chronic fear and anxiety, with serious long-term effects on health and other life outcomes (p. 1)

People with neurological differences are more vulnerable to being victimized, have increased effects from the trauma, and have much less attention paid to the influence trauma has had in their lives (Focht-New, Barol, Clements, Faulkner, & Milliken, 2008). People who experience trauma with or without a solid communication system may not be able to tell their stories, may not be believed, or may be powerless to do so. As a result, these people are inadequately supported.

The impact of trauma occurs from direct experience, by witnessing violence, and also by hearing about events. Neurotypical people might be able to handle life’s typical vicissitudes as they arise. However, some people with diverse neurosystems have had very different responses that are enhanced in the sensory system and compound the effects of disturbances in everyday life with difficulty rebounding. In addition to the traumas discussed below, loss with unresolved grief, natural disasters, being separated from family, environmental traumas, particularly in people with fragile or more sensitive sensory systems (e.g. lights, food, etc.), might be perceived by a person as traumatic. Trauma is defined by the effect it has on a particular person and not by the event itself.

Medical Intervention Traumas
Trauma comes in many forms. For people born with a range of neurological issues, medical treatment might be their first trauma. Even necessary medical interventions can leave a person traumatized.

Kate. Kate’s trauma history included three eye operations and multiple ear infections during the first two years of her life. There were also two difficult experiences in high school. One high school incident involved a peer, who acted out aggressively in class, triggering a “code red” alarm. This resulted in Kate’s fear of going to school and a state of hypervigilance, which seemed to continue into the present. The other event was centered around the impact of two rigid educators (according to Kate’s mother) in her senior year.

Kate’s behaviors included ongoing episodes of severe perseverative self-talk, during which she was not able to maintain any contact with a task or with other people. She also reverted to kicking other people, not only when upset emotionally (i.e., anger, jealousy, guilt, sadness), but also when excited. The kicking behavior appeared to be a release of various kinds of “emotional charge” (Barol & Seubert, 2010, p.162). We must appreciate the traumatic impact of medical interventions, which can be compounded by additional experiences of trauma.

Person to Person Traumas
Interpersonal violence is pervasive in our society. People with neurological differences are not seen as the same as others, as they do not “fit in.” Further trauma in this realm involves neighborhood and school violence, bullying, marginalizing, shunning, being ridiculed and/or humiliated, being forced to do what others think is “right,” watching violence in the media without an opportunity to process information, and hostile living environments. Interpersonal violence can leave a person reverberating with fear and anxiety and a belief that the world is dangerous.

Trauma by Behavioral Intervention
Trauma has resulted from many of the “interventions” that have been used to change a person’s behavior (e.g. negative reinforcement, ignoring, timeout, behavior-focused programs, punishment, deprivation, not being allowed to see family or friends, limiting choices, restricting movement). Innocent people might inadvertently be perpetrators when they disregard who the
person is by placing demands in an effort to make the person be “just like everyone else.”

**How we historically treated people added to their trauma.** With all our good intentions, we can do an injustice to people with neurological differences by reducing everything they do to behavioral and attention seeking motivations. It is more productive to think of people as “trying to survive” threatening or isolating environments.

We often hear from clinicians and administrators that, “You don’t need to read the person’s records. The past is the past, and not relevant to whom the person is today … we use behavior management techniques to change their manipulative and attention seeking behavior and that is all you need to be concerned about.” This stance was what we were taught when we started our work 40 years ago. We then received training in Normalization (Wolfensburger, 1972), which is still a vital part of our consciousness. We set up living environments that offered a more typical lifestyle: privacy, dignity, good food, things to do, more protection from harm, opportunities to communicate, and be understood and responded to. Many people showed dramatic improvements once their needs were better met.

We observed in our work, that although simple enrichment of the environment helped approximately 70% of the people we directly supported, about a third of the people we saw either did not improve or their behaviors became more challenging. Using only Behavior Modification, there appeared to be a downward spiral as frustrated support people resorted to increasingly restrictive procedures. One issue kept surfacing. Most of the people in this group had serious traumatic experiences in their lives that were not only not addressed, but also led to piling trauma upon trauma on the person often in the name of treatment. We recognized that peoples’ lives were influenced by how we thought about them.

**What Are the Consequences of Trauma to the Nervous System?**

Consequences of trauma are far reaching. More important the effects of unaddressed trauma are often pervasive and affect people in social, physical (even cellular), emotional, and psychological realms. Many trauma responses are processed in the nervous system. Understanding (and explaining) the impact of trauma to the nervous system is complex. Very simply, trauma is stored in our memory, which begins with input from the sensory system, is communicated to various parts of the brain and body, and then “reality is formed” (Rothschild, 2000, p. 39). Past trauma becomes a person’s lens for their present thinking, emotions, and actions and are often not consciously integrated. So, we see people who express themselves through their actions (e.g., challenging behaviors) without being able to explain what they are experiencing.

The sympathetic nervous system’s job is to ready us for fight or flight and is modulated by the parasympathetic nervous system. Finding a balance for the two is critical to our survival. When a person experiences trauma, their brain is changed (van der Kolk, 2014). This can mean that the sympathetic system is activated but the parasympathetic system is ineffective. “Long after the actual event has passed, the brain may keep sending signals to the body to escape a threat that no longer exists” (van der Kolk, 2014, p. 54).

**Impact with Neurodiversity**

People who are neurodiverse might begin with compromised nervous systems, powerlessness in their living and working environment, have pre-existing challenging behavior, and be limited in their means to express themselves. When trauma is layered on, effective coping strategies might not be available to trigger the parasympathetic system response. People respond with fear (sympathetic response) and develop ineffective coping strategies. Repetition and re-enactment of the trauma become central to the person’s life. The world feels unpredictable and random, a cornerstone of trauma impact.

The short and long-term outcomes of trauma might include: anxiety, arousal, depression, reduced immune system functioning, overwhelming emotions (fears), phobias, panic, drive to control, repetition of scenarios, inability to express trauma, and become shut down. These manifest in a series of generalized behaviors such as becoming a recluse, over responding, reacting in atypical ways, and rapid mood change. Trauma-based learning may result in a range of expressions such as ‘challenging behaviors’ (Focht-New, Clements, Barol, Faulkner, & Service, 2008,p. 5).

While trauma responses stemming from war, natural disasters, and interpersonal violence are becoming better understood along with the mind/body consequences of these acts, fewer sources for neurodiverse people are recognized. Traumas add up and they too need to be addressed for all people of all ages. In addition, documenting the person’s story is necessary in order to increase awareness of what the person has gone through. This information
should lead to a lens of empathy, education, and trauma informed care for the person and their supporters.

**How Can We Know If Someone Has Experienced Trauma?**

When we teach clinicians, we find that many come in with preconceived ideas that the people they work with are “manipulative.” However, when they delve into their stories via interviews with the person, family members and caregivers, and a thorough review of the records making meaning and “respectful guesses,” they often find underlying trauma that has not been addressed. The presumption of incompetence due to an intellectual disability as well as improper medication made it unlikely that anyone on her team would consider trauma as an underlying reason for her behavior. Angela’s story is an example of the need for a team approach and for considering trauma when working with individuals.

**Angela.** Angela, 17 years old, came to a group home from a large institution. At first, she presented as a person with minimal understanding and language abilities. She showed little emotion, her face looked blank. Her diagnosis was severe “mental retardation” and though there was no mental health diagnosis, she had been on Mellaril (an anti-psychotic often used for behavior control in people with the “MR” diagnosis) for years.

Once she moved into the group home, seeing no reason for the medication, the houseparent asked her community physician to discontinue the medication. Angela started coming alive. Her face showed animation, she showed interests, happiness, and started talking in sentences--sophisticated sentences, telling details of her life to the houseparent. Everyone who worked with her was thrilled. One day, while in the car, she told the houseparent that, as a child, she had been sexually abused by her father and her brother and that they had locked her in the closet rather than send her to school so that she couldn’t tell anyone at school about it.

The houseparent was stunned, thinking, I am only 22 years old. I have no training in this. I don’t know how to respond. She then replied, “I am so sorry that this happened to you.” Later, looking through the few records that were available in the group home, she pieced together enough of the puzzle to validate Angela’s allegations for the houseparent. Her father had taken her in for a hysterectomy when Angela was eleven years old. Later, she was dropped off at the institution, and never saw her father and brother again.

While initially life seemed much more promising for Angela, as the summer progressed, her behaviors started to change. She cut her own hair, close to her head in front so she “wouldn’t look pretty,” and she started making sexual advances to the other children in the house. This further evolved into staying up screaming at night, stripping and masturbating in public and then threatening others in the household with sharp objects. When the houseparent went for help, the local psychiatrist said, “The mentally retarded are like broken instruments - the air goes in one place and you never know where it is going to come out, so you can’t say that they have mental illness.”

Nowadays, it is easy to see the trauma story in Angela’s life. We can see that she never had appropriate trauma treatment, and instead, her whole life story was suppressed by the medication - leaving her no opportunity to process her past or to build a more enjoyable life. Multiple traumas create fertile ground for ongoing symptoms, almost anything can rattle the person, and very little helps them prior to trauma informed treatment.

**What Kinds of Therapies Help?**

There are a number of clinical therapies for treating trauma that benefit people who have a solid communication system, and most useful when they are combined with a therapeutic social living environment. Few practitioners are willing and available to work with people who are neurodiverse. Their training has not helped them in cross walking treatment paradigms with neurological differences.

Some of the most promising therapeutic practices do not require “talking!” These include Eye Movement Desensitization and Reprocessing (EMDR), biofeedback, neurofeedback, and body-focused work of various kinds. These approaches offer people ways to calm their sympathetic nervous system and develop the parasympathetic system (van der Kolk, 2014) to be more present in the world, to learn, and grow.

There are a number of other approaches that have helped with trauma. These include: exercise (walking is especially good), mindful breathing, hatha and other gentle forms of yoga, art, music, meditation, and bilateral stimulation such as tapping, walking, watching/ tracking visually cross the body’s midline, sounds (van der Kolk, 2014). The idea is to soothe, experience power over one’s self and one’s bodily responses by stimulating the
parasympathetic nervous system and avoiding hyper-responses. Twenty minutes often can be enough to reduce agitation and help people cope with problems and sleep better at night. Practice, practice, practice strategies when the person is doing well so that a brain pathway is developed and can be accessed later when upset or overwhelmed.

**Who Are the Social Therapists and What Role Do They Play in Healing?**

How a person interacts with another can build them up through recognition, comforting presence, respect, acknowledgment, and praise and offer calming techniques in the moment and throughout the day. Conversely “supporters” can break down a person by being abrupt, harsh, demeaning, punitive, demanding, and inaccessible. Therapeutic intervention really cannot make a positive difference if the person returns from the session to an environment that perpetuates lack of control, fear, pain, or irritation.

A social therapist is a person who directly interacts with a person on a regular basis in daily life who, with mindful use of self, uses interactions, voice, touch, eye contact, listening, mirroring, etc. to enhance a person’s positive sense of self and relatedness. A family member, teacher, direct supporter, or friend may be a social therapist as long as they are aware of and understand the consequences to and healing potential of their presence and interactions. We have found that for many people, especially family members, gifted empathetic teachers and direct-care givers, being a social therapist comes naturally. Sadly however, we have also found that these basic skills and approaches often have to be taught using a trauma informed context to help someone transform into a social therapist. Once that transformation occurs and the environment as a result feels safer, more responsive to needs, and trust worthy, the individuals we are hoping to support start to heal and outside therapies have a better chance of being effective.

While we profess to know that no two people are the same, in practice, we often take away people’s individuality even in the name of being progressive. For instance, the paradigm that all people must participate in group activities, disregards the needs of a person who is very uncomfortable being in contact with other people, who gets over stimulated by things such as noise and seemingly random movements. As the person tries to retreat, we pull them back to the very situation they are finding aversive. We see this in families, as a person is forced to participate in family gatherings when they are not ready, in schools when a student is made to sit in the circle with the other students when they need to sit at the periphery listening from afar, or in activities with others in service programs where again, the proximity of others feel very uncomfortable, even painful. In each case, as the person is coerced to “participate,” “acting out” to escape their overwhelming discomfort is their only option. Sometimes the judgmental response that the “manipulative person is just trying to get his or her own way” results in punishment.

When coming from an empathetic lens most direct caregivers, families, and teachers advocate for what the person is really asking for. These individuals who seek to understand the root causes of a person’s challenging behaviors offer comfort, connection, and an individualized approach. Meeting the person where they are currently, working through encouragement, accommodation, warmth, and caring, are characteristics of “social therapists.”

**Social Therapists**

Social therapists are however, often disrespected and ignored by the professionals that “know better” and by systems that have preconceived criteria about what children and adults should achieve and how they should behave. While traditional trauma and other kinds of therapies might be beneficial it is often one hour a week for a defined period of time and might not include friends and family who are with the person in their day-to-day lives. Social therapists are pivotal to the person’s success in navigating the trauma they have experienced.

Once the social therapists are helped to work from the trauma-informed paradigm, their observations and insights become the key to developing supports for a person who may not be able to clearly articulate their needs, desires, and concerns. The relationship that social therapists have with the person addresses key elements that have been violated by the trauma: being safe and feeling safe, building trust, setting boundaries, increasing internal resources (self-esteem and confidence), and finding power and control.

It is vital that the social therapist figure out the starting point when working with a person. This is a place where we meet the person, and when they are assured of safety and esteem, to help the person meet their own needs better. A social therapist who is integrated into daily life and helping the traumatized person in the moment is invaluable.
Peter. Peter was a young man on the autism spectrum who did not speak or use augmentative alternative communication beyond a few gestures and signs. He showed his distress by screaming and slapping his head literally thousands of times a day. In his past caregivers, and peers had mistreated him. He hated being around people. Peter would often come up to staff visually upset when around others and indicating he wanted his arms to be held behind him in a restraint. He would also try to hide under beds and tables. His family advocated that he be given a restraint jacket and be allowed to hide during group instruction. However, we, as the administrators and clinicians, would bring him out to be with people, thinking that he would learn more that way. We believed we knew what was best for Peter and told the parents that they didn’t know what they were doing.

Peter continued to injure himself. We realized that the whole time he was with others, he was hitting himself and 100% of the time oblivious to learning opportunities. We finally woke up and realized that while the means, a restraint jacket, that the parent were promoting were not ones we could condone, there was a real need there that we were not respecting.

We, with the parents’ joyous approval, put a mattress under the bed and told Peter that while we wanted to be with him, he could squeeze under the bed onto the mattress whenever he wanted to. At first he was squeezed in there almost all of the time. He was hidden from us, but he wasn’t head slapping. In a few days he began to emerge and join us for a few minutes at a time. When he was with us, he seemed relaxed and didn’t hit his head. He was really present. He learned more signs, helped set the table, smiled. And then, when showing signs of stress would retreat to his special space. Over the next few months the amount of time he was with us grew, and the time under the bed diminished. When he was with us, he was fully “present” In essence, once he had the opportunity to calm his sympathetic nervous system, he could become resilient to the omnipresent experiences of powerlessness that helps them to be fully seen and heard. It helps protect them from powerlessness when the task (i.e., tooth brushing, cooking, vacuuming and so on) is used as a vehicle for growth. The task is a way to show support and respect for the person we are with. We cause further wounding when the task is the prime object and the person’s needs are overridden in order to get the job done.

Creating safety, integrating soothing, creative, and interactive opportunities throughout the day, Judging whether to speak or not to speak, to use soft or excited tones of voice, to touch or not to touch, to provide reassurance, to choose specific tasks and activities, all are part of the unique relationship built by the social therapist. Trust is built, with predictability, and ultimately a sense of control over one’s life. We can facilitate healing and growth when the task (i.e., tooth brushing, cooking, vacuuming and so on) is used as a vehicle for growth. The task is a way to show support and respect for the person we are with. We cause further wounding when the task is the prime object and the person’s needs are overridden in order to get the job done.

Social therapy not only helps a person overcome the effects of trauma, but it also helps promote resilience in the face of life’s challenges. Focused, continuous, individualized, trauma informed supports encourage people throughout their lifespan in a way that helps them to be fully seen and heard. It helps protect them become resilient to the omnipresent experiences of powerlessness in everyday life that otherwise leave a person more vulnerable to severe traumatic responses.

Conclusion
Experiences of trauma are often at the root of challenging behaviors in people, resulting in heightened reactivity, a loss of trust in their world, and a feeling of a loss of control. While there are a growing number of therapies that are useful to help a person with symptoms resulting from trauma, many of these therapies are not readily available to people who are neurodiverse. When they are available these approaches are most beneficial when the daily life experience is supportive, and intentionally focused on countering the messages taken on through trauma, as well as developing the parasympathetic autonomic nervous system to reduce the arousal state of the sympathetic nervous system. It is
incumbent upon us to identify the effects of trauma to help the
social therapists to rally their full potential to accompany the
person through daily life toward undoing the effects of trauma as
the person works toward a healthy sense of self. Furthermore, we
must advocate for the use of the full range of supportive therapies
available to other members of society who have experienced
trauma.

References
Center for Disease Control and Prevention. (2016). The ACE study data, Kaiser
   What-is-Trauma/41/
   Approaches for intervention. Perspectives in Psychiatric Care, 44(2), 89-98.
   California: Author.
   National Institute of Mental Retardation.
 Organization Name (If applicable): ______________________________________________________________________________________

Organizational members must fill out the following fields for the Primary Contact only. To submit five staff members that would like to receive TASH benefits, please attach the Organization Member Sub-Account Form (available at www.tash.org/join).

First Name: _____________________________________________ Last Name: __________________________________________________

Address: __________________________________________________________________________________________________________

City/State/ZIP: ________________________________________________________________________ Country: _______________________

Phone: ______________________________________________ E-mail: _________________________________________________________

Membership Level
TASH offers membership at a variety of levels. Please review the details below and choose the membership level that is appropriate for you. Individual and organizational memberships are available. Membership dues can be paid annually or monthly. A complete summary of member benefits can be found at www.tash.org/join.

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<th>Membership Level</th>
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<td>$165 year $14 month</td>
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<td>Research and Practice for Persons with Severe Disabilities, the official TASH research journal (print copy)</td>
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<tr>
<td>Access to TASH’s professional network, forums &amp; blogs</td>
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<tr>
<td>Affiliation with a TASH Chapter (includes policy and expertise, Capitol Hill Days, Chapter communications &amp; activities)</td>
<td>X</td>
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<td>Advocacy Alerts &amp; Updates</td>
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Demographic Information
This information is collected for TASH’s use only so that we can better serve our members’ needs.

What is your race or ethnicity? (Optional; select all that apply)

- American Indian or Alaska Native
- Asian
- White/Caucasian
- Black or African American
- Hispanic/Latino
- Other ________________________
Which of the following best describes you? Select all that apply. (not applicable for organizational members)

- General Educator
- Special Educator
- Education Administrator
- Transition Educator
- University Faculty
- University Researcher
- Person with a disability
- Parent of a person with a disability
- Sibling of a person with a disability
- Other family member of a person with a disability
- Early Intervention Service Provider
- School-Aged Related Service Provider
- Adult Service Provider
- Government – Federal
- Government – State
- Other family member of a person with a disability
- Attorney
- Public Policy Advocate
- Student
- Other Advocate
- Other

How did you hear about TASH? ____________________________ How would you like to receive info from TASH? □ Email □ Postal

Please indicate your areas of interest. Select all that apply.

- Early Childhood
- K-12 Education
- Transition
- Post-Secondary Education
- Employment
- Community Living
- Aging Issues
- Advocacy
- Public Policy
- International Issues
- Assistive Technology
- Communication
- Diversity & Cultural Competency
- Human Rights
- Other

Additional Information

Your Date of Birth (Optional): ______/______/___________
If you are a family member of a person with a disability, fill out the date of birth of your family member: ______/______/___________

If you are a student, please fill out the following fields:

- University Name: ___________________________________________________________
- Expected Completion Date: ______________
- Major/Department Name: ___________________________________________________________

If you are a university educator, what is your field of study? __________________________________________________________________

Please indicate your areas of interest. Select all that apply.

- Early Childhood
- K-12 Education
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- Assistive Technology
- Communication
- Diversity & Cultural Competency
- Human Rights
- Other

Payment Information

Monthly membership must be paid with a credit card for automatic renewal purposes.

Credit Card (select card type) □ Check (make payable to TASH) □ Purchase Order

- American Express
- Visa
- MasterCard
- Discover

P.O. #: ____________________________ (send copy with membership form)

Card #: ____________________________ Expiration: ______________
Name on Card: ____________________________ CVV: ____________
Authorized Signature: __________________________________________________________________

Would you like to make a tax-deductible donation to TASH?

- $10
- $25
- $50
- $100
- $ ______

Total Payment (add membership total and donation, if applicable) $: ______________

Please submit this membership form via mail, fax or e-mail. If you have questions, please call (202) 467-5730 ext. 1309.

1101 15th Street NW, Suite 1212
Washington, DC 20005

Fax (202) 540-9019
E-mail info@tash.org

www.tash.org to learn more about TASH
www.tash.org/join for an overview of member benefits
NEW!

Welcome to TASH Amplified, TASH’s new podcast series. This series seeks to transform research and experience concerning inclusion and equity for people with disabilities into solutions people can use in their everyday lives.

Season One Episodes

- A Brief History of PBIS
- Teaching Math to Students with Disabilities: What We’ve Learned in 10 Years
- Reflections on 40 Years of Agency Community Supports
- Faith and Flourishing: Equipping Your Church to Reach Out to People with Disabilities
- Faith and Flourishing: Welcoming Children with Disabilities and their Families
- Faith and Flourishing: Hidden in Plain Sight
- Special Education Teachers and the General Education Curriculum
- What Matters to Family Members when a Relative Transitions to Community Living
- Building Communities to Support People with Disabilities
- Presentations on Recreation and Leisure for People with Disabilities at the TASH Annual Conference
- Barb Trader Reflects on a Lifetime of Accomplishment in Disability Rights

www.tash.org/amplified
TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

**Policy Statement**

It is TASH’s mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities. Items in this newsletter do not necessarily reflect attitudes held by individual members of the Association as a whole. TASH reserves the right to exercise editorial judgment in selection of materials. All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as “the mentally retarded,” “autistic children,” and “disabled individuals” refer to characteristics of individuals, not to individuals themselves. Terms such as “people with mental retardation,” “children with autism,” and “individuals who have disabilities” should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH’s publishing and advertising policy, please visit www.tash.org.

**TASH Mission & Vision**

As a leader in disability advocacy for more than 35 years, the mission of TASH is to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion. Together, this mission is realized through:

- Advocacy for equity, opportunities, social justice and human rights
- Education of the public, government officials, community leaders and service providers
- Research that translates excellence to practice
- Individualized, quality supports in place of congregate and segregated settings and services
- Legislation, litigation and public policy consistent with the mission and vision of TASH

The focus of TASH is supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people.

TASH has a vision of a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life. TASH envisions communities in which no one is segregated and everyone belongs. This vision will be realized when:

- All individuals have a home, recreation, learning and employment opportunities
- All children and youth are fully included in their neighborhood schools
- There are no institutions
- Higher education is accessible for all
- Policy makers and administrators understand the struggles of people with disabilities and plan – through laws, policies and regulations – for their active participation in all aspects of life
- All individuals have a way to communicate and their communities are flexible in communicating in alternate ways that support full participation
- Injustices and inequities in private and public sectors are eradicated
- Practices for teaching, supporting and providing services to people with disabilities are based on current, evidence-based strategies that promote high quality and full participation in all aspects of life
- All individuals with disabilities enjoy individualized supports and a quality of life similar to that available to all people
- All individuals with disabilities have the tools and opportunities to advocate on their behalf