Supporting Students With Autism Spectrum Disorder Through Grief and Loss

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Ms. Bellamy was a beloved high school teacher serving students on the autism spectrum, as well as a highly visible staff member on her campus, where she was the varsity tennis coach. Her unexpected death affected everyone on campus and across the broader community, none more so than the eight students with autism spectrum disorder (ASD) with whom she worked daily across the school year. Her colleagues, though devastated, rallied together to support the students as they learned of her death, processed their grief, and worked toward understanding their profound loss. The supports and strategies used to help "Ms. Bellamy's boys," as she fondly referred to them, can be used to support students of various ages across the spectrum as they grapple with loss of all magnitudes.

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All student populations require support from school staff during times of grief and loss. The grief process is highly personalized and depends on multiple factors, including the type of bond and relationship with the person, the student's prior experience of loss, and the age and developmental stage of the student (Quinn-Lee, 2014). Grief manifests differently in students but may be expressed as disinterest in class or previously preferred activities, withdrawal, fear of separation from others, anger, guilt, risk-taking behavior, and anxiety (Schonfeld & Quackenbush, 2012). Schools can serve as an important source of support for students who may be demonstrating some of these responses and can provide a safe place for students to grieve (Holland, 2008). Research indicates that allowing students to seek support from school staff—typically, a social worker, teacher, or counselor—can support their well-being throughout the grieving period and beyond (Lawhon, 2004).

Recommended supports at school include partnering with families to develop a grief support plan, creating a special location for grieving students to go when seeking relief, individual counseling, empathetic listening, and teaching about death and dying through books and classroom materials (Lawhon, 2004). In addition, a number of strategies can help prepare students before a loss occurs, such as incorporating literature into classroom curricula that addresses death or loss (e.g., *The Fall of Freddie the Leaf*, Buscaglia, 1982; Walker & Jones, 1986) and including lessons related to the biological understanding of death as it occurs (e.g., life cycle in science class, observing a dead bug on the playground; Renaud, Engarhos, Schleifer, & Talwar, 2015).

Grief and Loss in Students With Disabilities

The grieving process for students without disabilities, though personal and complex, is well described in the literature. There is less research examining the grief process and the necessary supports for students with disabilities. Students with developmental or intellectual disabilities experience grief, and many students with disabilities experience the same degree of emotions and behavior changes as those without identified disabilities (Gilrane-McGarry & Taggart, 2012). However, owing to difficulties with communication, comprehension, and lack of support and understanding from others, individuals with disabilities may also present challenging behaviors, such as aggression, self-injurious behavior, and disruptive behavior during periods of grief (Gilrane-McGarry & Taggart, 2012). Unfortunately, research indicates that caregivers and school personnel typically do not recognize the increase in challenging behaviors as expressions of grief, and these responses may be minimized, misinterpreted, or attributed to the disability rather than to grief (Hollins & Esterhuyzen, 1997).

Historically, individuals with disabilities have not had access to appropriate supports during times of loss or grief, often being excluded from rituals related to loss (e.g., funerals), not being prepared for an inevitable loss, not being provided supports or time to process the emotions related to grief, and, in some cases, not being told of the loss if staff or caregivers deem that the individual has a limited understanding of it (Gilrane-McGarry &

Taggart, 2012). More recently, however, school staff have recognized the importance of supporting individuals with disabilities through the grief process and are providing supports with evidence of efficacy, such as supportive counseling (Lawhon, 2004), participation in rituals around the loss (Quinn-Lee, 2014), use of photos or other personal mementos (Gilrane-McGarry & Taggart, 2012), and education and preparation around death and dying (Blackman, 2008).

Grief and Loss in Students With ASD

The needs of students with ASD during periods of grief and loss are relatively unexamined. Whereas some students with ASD may face challenges related to comprehension and communication similar to those affecting students with intellectual and developmental disabilities, others may face several different or additional challenges in understanding loss and processing grief. First, students with ASD often struggle in understanding abstract language and concepts (Mesibov, Shea, & Schopler, 2005). Some discussion related to loss may include concrete terms (e.g., "Ms. Cerini had a baby and is at home taking care of him"), yet other conversations around loss, such as death, may be more abstract and difficult for students with ASD to understand. Next, impairment in social reciprocity may inhibit students' ability to connect with others during the grieving process or to recognize and empathize with the grief of others, given that perspective taking is an identified difficulty. Deficits in social communication may impair their ability to express their feelings during the period of grief; thus, students with ASD may miss out on the community of support that forms during times of loss. In addition, students with ASD often demonstrate rigidity and insistence on sameness and may feel great distress when loss disrupts their daily routines. Last, students with ASD have a greater likelihood of comorbid anxiety and depression than do other populations (Mazzone et al., 2013), which can be exacerbated during grief periods, especially when paired with limited coping skills (Jahromi, Meek, & Ober-Reynolds, 2012). These challenges are illustrated in first-person descriptions of the grieving process for individuals with ASD (see sidebar).

An additional point for consideration relates to the magnitude of loss. Although this article focuses on loss in relation to major life events such as death, illness, and large life transitions (e.g., moves, job transfers), students with ASD may experience loss around smaller changes, such as moving to a new grade within the school, transitioning to a new babysitter or caregiver in the home, ending a preferred activity or event (e.g., LEGO camp), or misplacing or breaking an item of great importance (e.g., an iPad that is commonly used, a cherished toy related to a special interest, a favorite video game). The difficulty with change that students with ASD may experience may intensify their feelings of loss when coupled with an often intense attachment to objects and interests (Szatmari et al., 2006). Although it may be difficult for others to adequately empathize with these losses, it can be helpful for school staff members to view these smaller losses as important and to apply the following relevant strategies when appropriate. For additional strategies for supporting students with ASD through these "smaller" losses and transitions, see Hume, Sreckovic, Snyder, and Carnahan (2014).

Support Strategies for Students With ASD

The supports described previously for students with and without disabilities (e.g., empathetic listening, counseling, preparation) can and should be applied to students on the autism spectrum. Specific adaptations and additions may be beneficial to best meet the unique needs of these students. Several are described here, along with a glimpse of how the staff at Ms. Bellamy's high school worked together to support her students as they grieved the loss of their teacher. For additional resources to facilitate the implementation of these strategies, see Table 1.

How Individuals With Autism Spectrum Disorder Describe Their Experiences With Grief

> You see, every brain only has so much space in which to process information, and if a very large part of that is consumed with emotions, it can easily result in failures of other areas. What this looked like to the rest of the world is that my autistic symptoms worsened . . . and they did. I had less ability to process information and therefore less ability to be social or to do any tasks. (Fisher, 2012, describing her response to her father's death)

> While my family members struggled with the first four stages of grief, I only struggled with one. **Depression** . . . hit me like a brick wall. Overwhelming sadness consumed me. I felt immobilized by my sadness. Immobilized and confused. . . . I felt like every ounce of my energy was poured into processing the depression I was feeling. (Schultz, 2014, describing her response to her niece's death).

> I did . . . grieve a little. I cried. I lamented about not having gotten to know her better because she seemed like a great person. . . . I also found myself recreating the accident in my mind. I wondered what her last thoughts where and how quickly she died. I tried to picture exactly how the accident played out. I wondered what her body looked like. . . . Why? This is not some perverse fascination with death. It is because I have such a hard time wrapping my head around how someone can be alive and happy one minute and essentially cease to exist the next. (Anonymous, 2011, describing her response to the news that an acquaintance had died in an unexpected accident).

Strategy #1: Build a Team

After learning of Ms. Bellamy's death, a team quickly formed at the school to begin developing and implementing supports with the students. The team included the school psychologist, a speech

Table 1. Resources for Staff, Families, and Students

Resource	Description
Web sites	http://www.ukautism.org/pdf/compass/understandingdeath.pdf A brief overview of helping people with autism spectrum disorder (ASD) understand death, with additional resources. https://www.autismspeaks.org/helping-child-tragedy School psychologists via Autism Speaks share suggestions to caregivers to help individuals on the autism spectrum deal with tragedy. http://www.pathfindersforautism.org/articles/view/parent-tips-death-and-grieving The Pathfinders for Autism Resource Center provides tips for parents as their child with ASD deals with death and grief. http://expertbeacon.com/advice-providing-grief-support-kids-autism-spectrum/#.VOs5fi5WKu8 A counselor provides advice to support a child with ASD through the grieving process. http://autismnow.org/blog/bereavement-and-autism-a-universal-experience-with-unique-challenges/ An adult with ASD writes on the experience of grief due to loss of a loved one.
Books	Mellonie, B. (2009). *Lifetimes: The beautiful way to explain death to children*. New York, NY: Bantam. Faherty, C. (2008). *Understanding death and illness and what they teach about life: A practical guidebook for people with autism or Asperger's, and their loved ones*. Arlington, TX: Future Horizons. Lipsky, D. (2013). *How people with autism grieve, and how to help: An insider handbook*. London, UK: Kingsley. Markell, M. A. (2004). *Helping people with developmental disabilities mourn: Practical rituals for caregivers*. Fort Collins, CO: Companion Press.
Video Clip	http://www.autismsupportnetwork.com/news/video-dr-tony-attwood-autism-death-parent-38490234 Dr. Tony Attwood advises about the impact of a death of a parent on a child with ASD.
Sample Social Story	http://www.pathfindersforautism.org/docs/social-story-about-death.pdf

language pathologist, two classroom paraprofessionals, a special education department chair, a district-level crisis team member, a building administrator, and a faculty member from a local university with autism expertise. The team was armed with an understanding of how students generally may process loss and grief, as well as with its combined expertise in understanding ASD broadly and the needs of these students specifically. The team created an outline for a plan, which began with letting the families know and included how to share the news with the students when they returned to the classroom, how to staff the classroom in the first week, and how to create opportunities for students to express their feelings during the weeks and months ahead.

Research indicates that a team approach is essential in supporting students through the grieving process (Lawhon, 2004). Team members may include school social workers, school counselors, district-level staff trained in crisis support, classroom teachers and paraprofessionals, related service providers, family members, peers, and others who know the students well. The team can develop a plan of action to ensure that staff is sharing the news in a consistent fashion and that students are afforded ample opportunity to express their loss in different ways.

Strategy #2: Consider Your Language

One of the first decisions that the team had to make was how to tell the families and students about Ms. Bellamy's sudden passing. Team members decided to call the families and allow them to share the news with the students first. This would allow the families to personalize the news with their religious or spiritual beliefs. The team's discussions brought to light several important issues related to how to discuss the death with the students in the upcoming weeks.

Describe the loss in concrete language and terms, and avoid flowery or abstract phrasing. Differentiating between permanent and temporary loss is important. If the loss is temporary (e.g., a favorite teacher is going on maternity leave but will return), phrases such as "When we meet again" and "We will all be reunited" are appropriate. However, if the loss is permanent (i.e., death), those phrases, though spiritually meaningful for many, may be difficult for students with ASD to understand. The understanding of abstract phrases and metaphors (e.g., "She is in a better place," "She passed away") can be difficult for students with ASD and can create confusion (Lipsky, 2013). Even the term "loss" can be confusing for some students (e.g., "We lost Ms. Bellamy last night"), given that

students may assume that once she is "found," she will return to the classroom. For permanent loss, using direct and clear language is recommended (Faherty, 2008). Phrases such as "We will not see Ms. Bellamy again; she died" or "Ms. Bellamy's heart stopped working," though harsh sounding, may be easier for students with ASD to understand. See Figure 1 for an example of the language used with Ms. Bellamy's students.

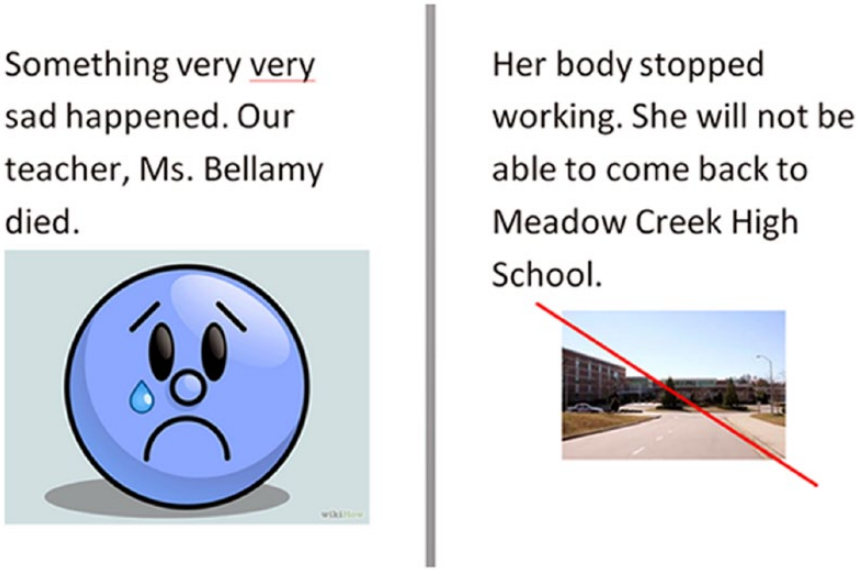
The understanding of abstract phrases and metaphors (e.g., "She is in a better place," "She passed away") can be difficult for students with ASD and can create confusion.

Because families understand death and what occurs after it differently, using language about heaven, the afterlife, or angels is not recommended; however, reminding students that they can always reflect on the fond memories that they have of their teacher, friend, family member, or pet to feel close again can be helpful (e.g., "Think about the fun things that you did with Ms. Bellamy. That can help you when you are feeling sad"; Faherty, 2008).

Strategy #3: Don't Take It Personally

When the students in Ms. Bellamy's class returned to school after learning the news from their families, their responses varied. Staff and students from throughout the school came by the room to express their shock and sadness. What struck some of Ms. Bellamy's tennis players, who were visibly upset and crying, was how calm and even happy some of the students in Ms. Bellamy's class appeared. There were murmurs that the students with ASD appeared to be insensitive or uncaring. The team then realized that its role would need to extend beyond helping the students with ASD through this loss; it must also include educating the staff and student body about how students with ASD may process grief and respond to others who are grieving.

Figure 1. Language Used About Ms. Bellamy's Death With Her Students



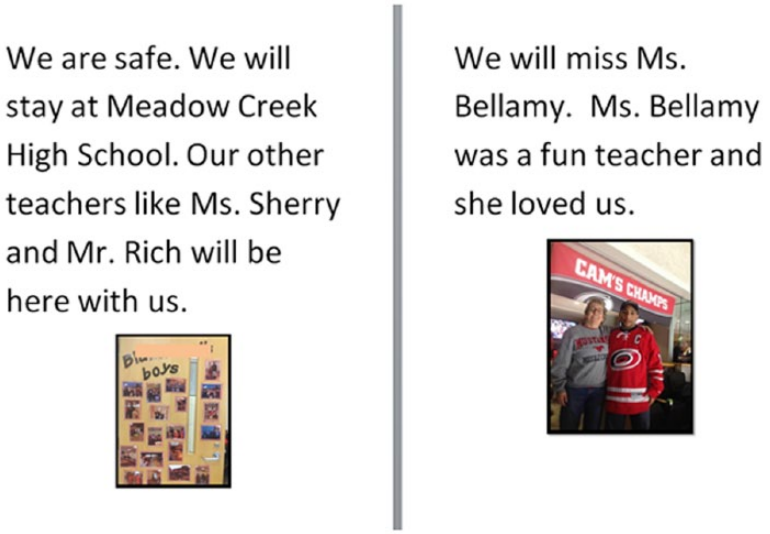
Students with ASD may not respond to news of loss or to the grief of others following typical social customs or protocols (e.g., "I'm sorry," sad facial expressions, crying). In fact, research indicates that in times of stress or anxiety, individuals with ASD may react unpredictably, such as laughing, smiling, or talking about topics that may be perceived as insensitive or inconsequential (e.g., asking questions about how the person died or the burial process, inquiring about a new video game; Faherty, 2008). Research indicates that persons with ASD have greater difficulty identifying and describing emotion words, as well as perceiving and mirroring the emotions of others (Moseley et al., 2015). Whereas teaching appropriate responses and social norms may be a goal for team members, it is important that staff, peers, and family members do not interpret other responses as a lack of care or concern about the loss or the needs of the bereaved. These responses do not indicate a lack of feeling or grieving and may in fact signal feelings of unease, nervousness, and being overwhelmed. The team may need to educate and prepare others about this potential response and, when appropriate, help the student with ASD understand her or his response as well (Blackman, 2008).

Strategy #4: Support Understanding and Opportunities for Expression

The students in Ms. Bellamy's class knew that she had a heart attack. Several students understandably had questions. One student, Sam, became very worried and began asking questions about safety and defending oneself. After further discussion, the school psychologist realized that Sam did not understand what a heart attack was. Sam knew that the word attack *indicated that someone or something would "pounce" on you unexpectedly, and he was worried that he and his family might not be safe. The team realized that even though it had used very concrete language to describe Ms. Bellamy's death, further supports were necessary to increase students' understanding and to allow opportunities for students to express their worries around the loss.*

Students on the autism spectrum benefit from receiving information in multiple formats because they often have receptive language deficits (Mody et al., 2013). To enhance

Figure 2. Social Narrative Used With Ms. Bellamy's Students



understanding, the team developed a series of *social narratives*—stories that clarify social situations and possible responses through modified text, photos, or the use of technology (Wong et al., 2014). These narratives were developed to give the students more information about Ms. Bellamy's death, to reassure them that they were safe, and to provide not only insight into how they may be feeling but also assurance that those feelings were normal (see Figure 2). Additional narratives were developed to provide ideas on what the students could do when feeling sad or overwhelmed with grief. The narratives were read individually with each student during the first weeks after Ms. Bellamy's death, copies were sent home to families, and copies remained available in the classroom across the semester. Although these were provided in print form, research indicates that social narratives can be effective in video and PowerPoint format as well and can be modified to meet the student's comprehension level (Lipsky, 2013).

In addition, the students were provided many opportunities to express their feelings as they were able—through group and individual discussions, writing activities and art projects (e.g., creating cards and tributes that students kept and distributed to Ms. Bellamy's family and close colleagues; see Figure 3), the creation of a class and schoolwide memory book (see Figure 4), and participation in a number of class and schoolwide rituals to honor their teacher. Opportunities for expression should be provided for students across communication abilities because more than half of the individuals identified as having ASD may lack the basic verbal and nonverbal skills necessary to express basic needs (Ganz et al., 2011). These opportunities may include alternate forms of expression, such as the use of augmentative and alternative communication (e.g., iPad, pictures); listening to or playing music; dance; yoga; and various visual art forms. In addition, staff should recognize that an increase in challenging behaviors may be an expression of grief and ensure that adequate support strategies are in place.

Strategy #5: Honor Routines

An important decision that the team had to make was what to do with the students when they returned to school following Ms. Bellamy's death. What should their schedule look like? What should the team do with the classroom and Ms. Bellamy's personal items and photos? Who should be providing instruction in her absence? The team decided to maintain the students' schedules as much as possible, adding activities each day to provide explicit supports for them. The team decided that extra staff was needed in the classroom, so a district-level crisis support staff member joined the team for the week, as did the speech-language pathologist. However, the paraprofessionals—who were well versed in the classroom routines and were closest to the students—provided the primary instruction, whereas the special education department chair assisted in organizing content. Other team members provided consultation and support as needed, and teachers from across the school volunteered to give up their planning periods to supplement instruction or offer enrichment activities (e.g., cooking activities from Home Economics teacher, Spanish lessons from the Spanish teacher). Everyone was committed to helping the students maintain their school day routines when possible, despite the devastating change.

In times of loss, people often abandon typical routines to instead gather to share memories and stories. These social activities may provide comfort during times of transition or loss, and people frequently perceive their daily rituals and routines as trivial and unnecessary in times of grief (e.g., a spelling test feels unimportant to administer when one receives news of a loss; Lipsky, 2013). Activities may be canceled or adjusted during periods of loss and grief in an effort to reduce the stress of those affected (e.g., the students might be too upset to go to physical education, so it will be canceled). Although it is important to create time and space for students to process loss and grief, students with ASD may cope best when daily routines are only minimally interrupted. Routines can provide comfort for students with ASD (Faherty, 2008) and may allow them to better express their feelings related to the loss. For example, instead of suspending academic instruction such as a writing lesson, adjust the content to relate to the loss and the associated feelings, such as a journal entry about favorite activities with the family member, friend, teacher (see Figure 5), or pet. Combining the stress of the loss

Figure 3. Sample Writing and Art Project

with the addition of changed routines—especially if the new activities are nebulous and unstructured, such as chatting about the loss or the grief—could exasperate or extend the grieving process (Lipsky, 2013).

Strategy #6: Include Students in Rituals and Ceremonies

Although the team members honored the need to preserve routine, they also wanted to build in opportunities for the students to participate in and create their own rituals. The student body was invited to the funeral, though few attended, so the team began to work on a memorial in which the students could take an active role and honor Ms. Bellamy in a meaningful way. Several weeks after her death, the team and the students raised funds to buy a bush with blooms that were the color of Ms. Bellamy's favorite university team. The students selected a location outside their classroom to plant the bush, and they created invitations for a smaller group of staff members and tennis players to attend the planting. Each of Ms. Bellamy's students helped to scoop out the dirt for the planting and to install the commemorative plaque.

Across cultures and customs, there are rituals related to loss, from jovial going-away celebrations when people are moving to solemn events such as a wake or funeral when someone dies. These rituals bring people together in expressing shared emotion, and research indicates that participation in these rituals can be integral in the healing process (Gilrane-McGarry & Taggart, 2012). The instinct of families and staff members may be to exclude or shield students with ASD from participation in these rituals, owing to the sensory stimuli; the perception that students may not understand the ceremony; or the notion that students may not fully understand the loss and, thus, the ritual may not be meaningful. Although these perceptions may be accurate for some students, including students with ASD in these rituals should be the initial expectation. Student participation in the ritual can vary per student need, with some students playing an active role for the full duration and others participating in a concrete task associated with the ritual and then departing. For example, some students may attend the school-level memorial service for a staff member who has died, whereas others may carry flowers to place in a vase at the service and stay during an opening poem or reading.

Beyond the community- and school-level rituals and ceremonies, staff members may want to consider designing and planning their own with the students. These rituals and activities can include students' unique likes and dislikes and can be individualized to the specific loss. These could include releasing balloons in remembrance of someone, participating in a favorite activity in honor of someone (e.g., eating at a favorite restaurant of a teacher or friend who has moved), participating in a charity event or service project to pay tribute to someone (e.g., walking in a breast cancer walk to support a teacher on medical leave), or creating and hanging a piece of art that can serve as a memorial. Consider the use of music, video, photos, web sites, writing, storytelling, and memory objects in the ritual or ceremony as vehicles to include students with ASD.

Strategy #7: Prioritize Coping and Calming Skills

The team noted increased agitation in some of the students in Ms. Bellamy's class in the weeks following her death. Some students cried when talking about her; one student began asking repetitive questions about the health of his mom and his other teachers; several became quieter and more withdrawn; and one student had frequent explosive outbursts related to usage of the class laptop and iPad. Team members recognized all of these as normal grief responses and ensured that they listened (to both words and behavior), responded with empathy, and communicated regularly with family members about how students were

Figure 4. Student Working on Classroom Memory Book

Figure 5. Sample Writing Activity

responding. They also increased the teaching and usage of coping and calming skills for all students in the classroom.

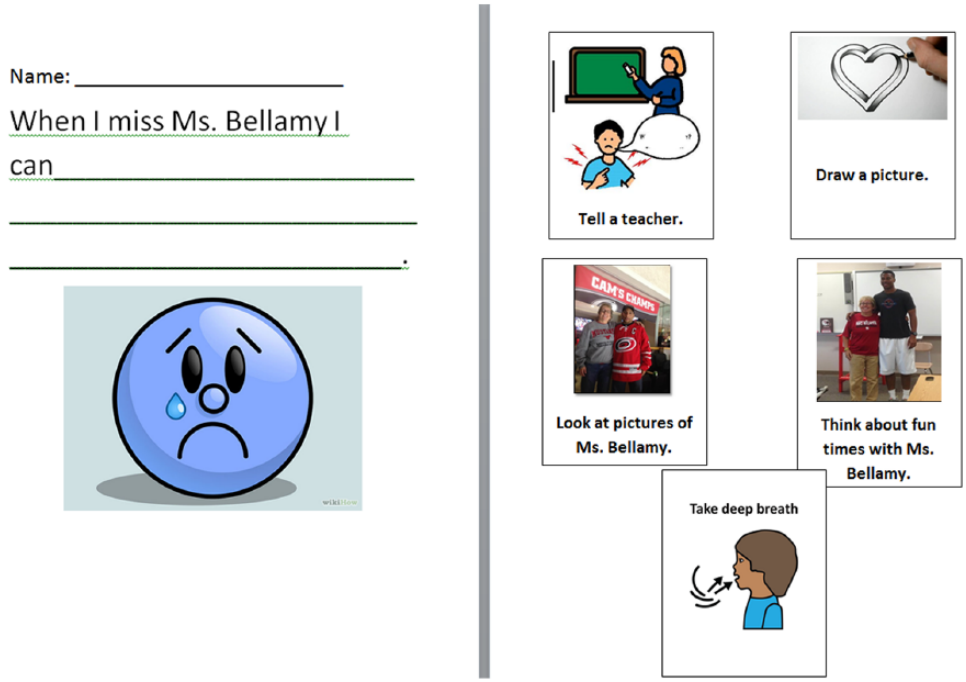
Instruction related to coping, self-management, and self-care is a priority in any program serving students with ASD, and it gains additional importance during times of grief or loss. Ideally, students will have coping and calming strategies in their repertoire of skills prior to the loss that they can access with support during the difficult period. These may include asking for a break, rocking in a rocking chair, listening to music on headphones, going to the hallway to get a drink, deep breathing, meeting with a preferred staff member, brief periods of vigorous exercise, or accessing a preferred activity or material (see Figure 6). If coping or calming strategies have not yet been introduced to students, team members should prioritize the teaching of these skills in the period following the loss, choosing times of the day when students are calm to initiate the instruction. Ensuring that students have ample access to these calming activities during the grief process is key, as is teaching students how and when to access these appropriately and how to reengage in scheduled activities, given that extended periods of "downtime" may not be therapeutic for many students with ASD (Lipsky, 2013). These may be scheduled regularly throughout the day in the initial weeks following the loss; then, if appropriate, staff may introduce and teach a self-management plan that helps students track their grief responses and feelings and identify when the calming strategies are required. Several existing tools, such as *The Incredible 5-Point Scale* (Buron & Curtis, 2003) and *How Does Your Engine Run?* (Williams & Shellenberger, 1996), can be modified to address sadness and anger associated with grief. Both tools use concrete and visual examples to teach students how to recognize their states of regulation and how to respond to emotions such as sadness, anger, and anxiety.

Teaching and reteaching other skills related to the management of an increase in challenging behavior will likely be required for some students. The team may need to conduct a functional behavioral assessment (Collet-Klingenberg, 2008) or craft a revised behavior intervention plan to reflect the mounting grief and its manifestation in a student's behavior. The team may decide to implement a research-based intervention or curriculum related to coping, such as *Coping Cat* (Kendall & Hedtke, 2006) or *Facing Your Fears* (Reaven, Blakeley-Smith, Nichols, & Hepburn, 2011), each based on the principles of cognitive behavior therapy (Wong et al., 2014) and proven supportive of students on the autism spectrum. Each curriculum teaches ways of coping with anxiety and fear through the use of cognitive and behavioral strategies, such as modeling, guided imagery, simulation, real-life exposure, role-playing, relaxation training, and reinforcement.

Strategy #8: Be Aware of Changing Behaviors

The school team implemented a number of strategies to support the students in understanding and expressing grief and provided instruction and practice related to coping skills. A number of students were responding, but several concerns for student well-being remained. In the months after Ms. Bellamy's death, the team noticed that Calvin, a student who was nonverbal, began to get stuck in repetitive behavior patterns, particularly buttoning and unbuttoning his pants. He was having difficulty moving on

Figure 6. Coping Strategies Implemented With Ms. Bellamy's Students



from this behavior and was less responsive to prompting from staff members to reengage in classroom activities. Although Calvin had engaged in occasional repetitive behavior, the intensity, frequency, and duration of the buttoning increased after Ms. Bellamy's death and was concerning for the team. Staff spoke to the family, who was seeing an increase in similar behaviors at home. The team determined that this increase was likely related to the loss Calvin was feeling, and the family decided to seek additional support outside of school from medical personnel.

Students with ASD may not be able to verbally express their grief, so these expressions may be demonstrated through other means. The team should be keenly aware of the behavior of students with ASD following a loss and alert for signs of anxiety and depression. These may include a change in sleeping or eating patterns, increases in repetitive behaviors, excessive worry or rumination, increased agitation or irritability, or decreases in self-care (Hedges, White, & Smith, 2014, 2015). When these behavior changes are observed, it is essential that the school and family communicate openly and regularly. Support from mental health and medical providers, such as a family doctor, therapist, psychologist, or psychiatrist is warranted because a student may require more support or different types of support (e.g., regular therapy, regular exercise, medication) than what the school team can provide. Finding providers with expertise in both ASD and related mental health concerns is important.

Conclusion

Research indicates that students benefit from receiving support from school staff during times of grief and loss (Holland, 2008). This support, best provided by a team of school-based staff, may need to be adapted to ensure that students with ASD experience those benefits. Inclusion in rituals and routines, as well as supports related to understanding, expression, and coping, will allow students with ASD to better understand the loss, process their grief, and practice coping skills that are applicable across the various losses that they may encounter across their school careers and beyond.

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