



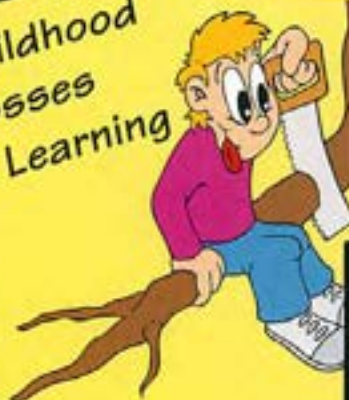
JENISON AUTISM JOURNAL

**Creative Ideas
in Practice**

Formerly **THE MORNING NEWS**
Jenison Public Schools, Jenison, MI Vol 15 #1

**Loss & Children
with ASD**

Childhood
Losses
& Learning



**Appreciating
the Differences**

**CHILDREN
AND
DEATH**



JENISON AUTISM JOURNAL

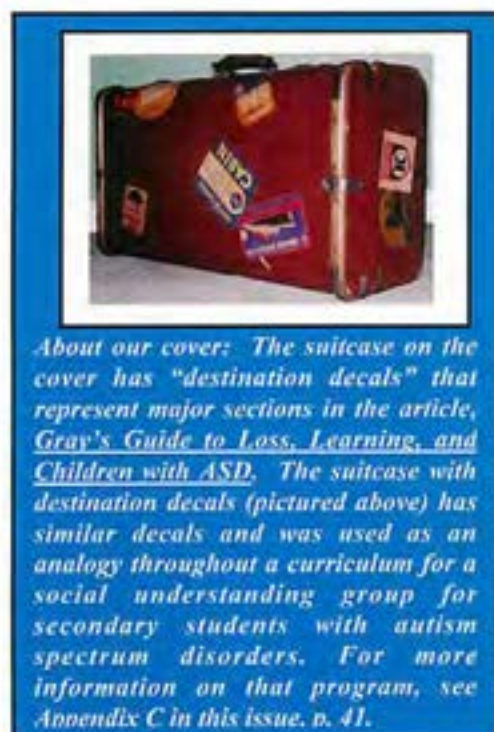
Creative Ideas in Practice

Formerly THE MORNING NEWS
Jenison Public Schools, Jenison, Michigan USA
Spring 2003 Volume 15 Number 1

Complete in this issue:

Gray's Guide to Loss, Learning & Children with ASD

This issue of the Jenison Autism Journal is affectionately dedicated in memory of Mr. Terry Arnold.



About our cover: The suitcase on the cover has "destination decals" that represent major sections in the article, Gray's Guide to Loss, Learning, and Children with ASD. The suitcase with destination decals (pictured above) has similar decals and was used as an analogy throughout a curriculum for a social understanding group for secondary students with autism spectrum disorders. For more information on that program, see Appendix C in this issue, p. 41.

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Editor: Carol Gray Design Editor: Sue Jonker Pen Pal Registry Editor: Karen Lind Logo: Janet Williams

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Jenison Autism Journal

Spring 2003

- Carol Gray, Editor

Welcome to the spring 2003 issue of the *Jenison Autism Journal*, and the third *Gray's Guide*. Recently, I was asked why some of my articles are titled as *Gray's Guides* and others are not. Actually, the *Gray's Guides* share a few common characteristics. Each tackles an important but uncharted topic. For example, *Gray's Guide to Compliments* was the first social workbook for adults, and *Gray's Guide to Bullying* was among the first articles on peer violence and children with ASD. *Gray's Guides* are a search for practical answers to tough questions that "keep cropping up" in my work. They are a chance for me to blend research with experience - both mine and yours - to uncover new solutions. In this Guide, we discuss loss, learning and children with autism spectrum disorders (ASD), to help them "move through" and learn from life's setbacks.

In the midst of writing this article, I received a call from the United Kingdom informing me that a dear friend of mine, Terry Arnold, had died. I am saddened by his passing, but very happy that he was my friend. I met Terry and his wife, Eileen, a few years ago on my first trip to the United Kingdom. A little apprehensive about what's what in England, Terry and Eileen graciously introduced me to great pubs and little-known but fascinating sights. It didn't take people long to get to know Terry - or the other way around. Terry had a calm, unassuming quality that made every minute important. He was a wonderful listener and gentle individual; definitely one of the world's unsung heroes in his work on behalf of children. As I get ready to head back to the United Kingdom this June, I know it will be difficult to pack the suitcase knowing Terry will not be there. While it can't be the same as it was before, if I remember all that he taught those of us who had the privilege to know and love him, the difference will be easier to negotiate. Terry was always on time, always where we needed him, always looking out for children. We should all do as well. For these and many other reasons, this issue of the *Jenison Autism Journal* is dedicated to my friend, Terry Arnold.

Working on this article caused me to re-visit losses in my own life, and what I have learned from them. My mother died a little over a year ago; she was my best teacher. I wrote a tribute that was read at her funeral, describing an indelible childhood memory. My mother was an amateur photographer, and would develop her photographs in a "darkroom" in our home. It was here that I learned my earliest life lessons. In order to be allowed to stay with Mom in the darkroom, I had to be absolutely still - quite a task for me! What follows is an excerpt from my tribute to her:

If you are to make the most of life, you have to understand time, patience, and their relationship to one another. There was no more unique teacher as to the lessons of time and patience than Mom. For me at the age of four through seven years, the most coveted seat in our home was the metal stool with the red seat in the darkroom, where mom developed her photographs. This seat had rules: sit very quietly, don't distract mom, and keep the darn door closed. Unwanted light was the enemy.

In a darkroom, time and sequence are governing principles. All steps of developing a picture had to be completed, and in the right order. To rush would ruin the outcome; to skip a step would prevent a photo from appearing altogether. In the black of that darkroom, with light enough to make interesting shadows while protecting new images, I would listen to my mom count. One thousand one, one thousand two, one thousand three... In a place where for me time stood still...mom counted its passing with deliberate care. No matter how many times I watched, the darkroom routines and rules held me in awe. Definitely more than worth the effort of keeping a young mouth closed and a small body still.

The final revisions in this issue were made on Mother's Day, 2003. Personally, it was a day I have been dreading a bit, saddened that this would be the first Mother's Day that Mom is not here and I am unable to say "thank you" as in years past. At least, that's what I thought. I went to the store, purchased a helium-filled "Happy Mother's Day" balloon, tied a note of thanks to the string, and released it outdoors. I wish I could take credit for this ingenious way to send messages to my Mom in Heaven, but, it's not mine - as you will discover in this article.

As I mentioned, characteristic of all *Gray's Guides* there are other ideas that are not mine on these pages. This article contains ideas contributed by people all over the world, with draft reviews by several patient friends, and the unfaltering support of my husband, Brian. I had hoped to list each name, but space simply does not permit. Websites are different, though - there's always room there. Please go to our website, www.TheGrayCenter.org where I have taken the opportunity to thank everyone personally. My only fear is that I may have mistakenly forgotten someone. If so, please let us know at graycenter@triton.net and we will immediately correct the error!

Welcome to the spring 2003 issue of the *Jenison Autism Journal*. Look what we discovered this time!



Important people in my life (left to right): my niece, Analee; my husband, Brian; (me); my niece, Heather; my mom; my sister, Elaine; and my niece, Lauren.



Gray's Guide to Loss, Learning, and Children with ASD

- Carol Gray, Consultant to Students with Autism, Jenison Public Schools & Director, The Gray Center for Social Learning and Understanding

"Every time something is lost, something is found. That's the way life works here on planet Earth."

Imagine your life as a suitcase. On the outside are several decals (like those used years ago to indicate hotels and ports of call), each representing an important "destination" in your life. Some denote achievements: earning a degree, starting a family, or establishing a career. Others represent losses that have been placed randomly *without* your permission: misplacing a family heirloom, losing a competition, or the death of a loved one. Safely stored in your suitcase is what you have discovered and learned at each and every one of these "destinations".

Many people believe that we learn far more from our losses than our achievements. How we respond to life's setbacks has a dramatic influence on our lives and ultimately leads to new wisdom; your suitcase contains elements of an important and often overlooked curriculum of life and its losses. Whether you are a parent or a professional, what you are aware of is the challenge of sharing what you've learned with a child with an autism spectrum disorder (ASD). This article supports your efforts to guide a child with ASD through the unexpected twists and turns of each day, as well as life's "larger" unplanned losses, like critical illness and death. At a practical level, the goal is to prepare children with ASD for, and guide them *through*, unanticipated events - whether it is the loss of a bottle cap or a loved one. Over time, this translates into an effort to teach children with ASD to tie their experiences together to learn from them, to effectively handle life's unexpected destinations.

As a consultant to students with autism spectrum disorders, I began research for this article in response to several requests for help in explaining terminal illness and death to children with ASD. My initial research included a review of related articles and books. In addition, I collected anecdotes from parents and professionals - information that subsequently led to a broader topic for this article. Not only are we uncertain about how to guide a child with ASD through the terminal illness or death of a family member, classmate, or friend, we are also overwhelmed by the reactions of children with ASD - frequently of equal or *greater* intensity - to life's "smaller" day-to-day losses.

A children's book written by a rabbi and a priest, Rabbi Marc Gellman and Monsignor Thomas Hartman, titled *Lost & Found* (1999), emphasizes the learning opportunity inherent in *all* of life's losses. Unfortunately, aside from the work of Rabbi Gellman and Monsignor Hartman, very little has been written about typical children and their day-to-day losses. There is, however, research about how children understand *death* as they grow and this provides our "point of departure" for an exploration of *all* of life's losses and children with ASD. Using *traveling through and learning from* life's losses as a theme, this article is divided into six sections, each identified with its own "destination decal":

1. ***Childhood Losses and Learning*** discusses loss and its relationship to learning, setting the stage to help children with ASD grow through their losses;
2. ***Children & Death*** provides a frame of reference for our discussion of loss and children with ASD - describing the responses of typical children to death and suggestions for adults;
3. ***Loss & Children with ASD*** explores how children with ASD experience day-to-day losses and death;
4. ***Appreciating the Differences*** explains why children with ASD sometimes have intense and/or unique responses to loss and the implications this holds for those who work on their behalf;
5. ***Guiding Children with ASD through Loss*** shares five guidelines and several ideas to assist children with ASD with losses ranging from a misplaced Lego™ block, to the loss of a friendship, to death; and
6. ***Appendixes***, including: *Resources for Adults & Children (Appendix A)*, *Social Stories & Loss (Appendix B)*, and *Additional Ideas (Appendix C)*.

*From page 14 of *Lost & Found: A Kid's Book for Living Through Loss* by Rabbi Marc Gellman and Monsignor Thomas Hartman (1999).

Childhood Losses & Learning

**Nobody wins every game. Nobody aces every test.
Nobody wins every day.
Life is really more about losing than winning.*

Childhood Losses

Loss in childhood cannot be outrun by even the fastest sneakers; all children experience loss. For the purposes of our discussion, we'll consider childhood losses in two categories: *Day-to-Day Losses* and those that result from *Death & Dying*. Each is briefly defined in this section.

Day-to-Day Losses are common setbacks ranging from a misplaced crayon stub to a friend moving out of town; in other words, all losses except loss of life. Unwelcome and usually unexpected, day-to-day losses in childhood may include but are certainly not limited to (categories may overlap!):

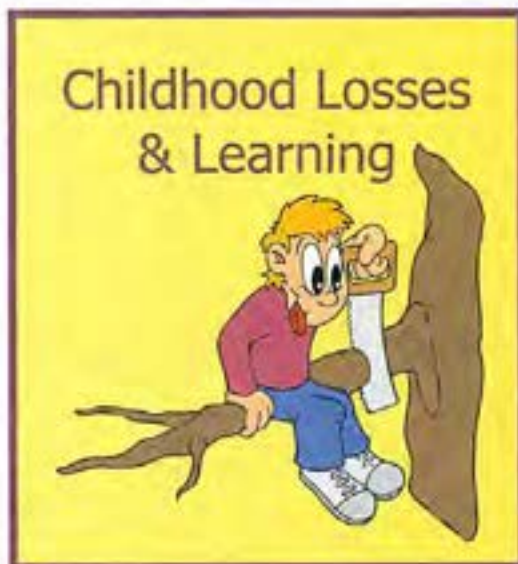
1. *Lost Stuff* (i.e. mittens, socks, toys, trading cards, lunch money, notes, school bags, mittens, crayons);
2. *Performance & Competitive Losses* (i.e. tests and assignments, playground games, talent competitions);
3. *Loss of Control* (i.e. place in line, unexpected circumstances, losing control of one's emotions);
4. *Loss via Sharing* (i.e. dividing a candy bar, taking turns on the swings, including a newcomer to an activity);
5. *Loss of Information* (i.e. homework, directions, computer files & discs, phone number of a friend);
6. *Lost Opportunity* (cancelled play date, rained-out ball game, loss of privilege due to reprimand);
7. *Loss of Routine* (i.e. substitute or supply teacher, temporarily leaving work on an assignment, holidays);
8. *Loss of Health or Ability* (i.e. flu, cancer, broken bones, loss of sight or hearing, amputation);
9. *Social Losses* (i.e. friendships, playmate moving out of town, loss of contact with a teacher at the conclusion of a school year, divorce and remarriage, older siblings moving away, missed meanings in communication);
10. *Emotional Losses* (i.e. loss of: patience, confidence, comfort, trust, security, respect, hope, humor).

Regardless of their severity, size, or form, losses come wrapped in *change* and require some form of *accommodation, adaptation or resolution* to get around, over, or - most importantly - through them.

Death is loss of life. As defined by Edgar Schneider, an adult diagnosed with high-functioning autism, death is "...when the laws of biology and chemistry come together to cause cessation of all functions of the body." (*Discovering My Autism*, p. 53). Our perception of death changes as we grow - infants, toddlers, school-age children, adolescents, and adults perceive and respond to death differently. People who have lost a loved one as a child and also as an adult, know in detail the contrasts of those memories. Most of us revisit important questions about our faith and relationship to others every time someone close to us dies, arriving at answers that reflect our advancing maturity, experience, and increasing wisdom. At any age death is a *non-negotiable* change. Due to the value we place on life and its social and emotional impact, death is regarded as a very serious loss in a category of its own.

Loss & Learning

Lost & Found, mentioned earlier, is a resource that expands our thinking and provides a philosophical framework for our discussion of loss. The authors guide children ages 8 through 12 through many of life's losses - beginning with "smaller" setbacks and gradually proceeding through loss of health to terminal illness and death - while providing support and reassuring insights each step of the way. In their opening comments for parents, they stress their belief that "...loss is an opportunity for learning..." that requires patience, builds confidence and skills, and teaches compassion. Three valuable themes are continually emphasized through the varied topics of each chapter:



*From page 30 of *Lost & Found: A Kid's Book for Living through Loss* by Rabbi Marc Gellman and Monsignor Thomas Hartman (1999).

1. All childhood losses are important. In the midst of handling adult concerns, a child's losses can seem relatively insignificant; hanging up the phone after consoling a friend recently laid off work, it may be difficult to appreciate the significance of a child's "smaller" setbacks. The distraught child who loses an action figure and recruits help from an adult (via words or behavior), is *not* seeking an estimation of the actual retail value of the missing object, or a monologue regarding the convenience of his/her current distress. The child is seeking something else, and, with help from an adult, has the potential of discovering more than just the lost action figure.

2. Loss is an opportunity for learning. At the very least, most losses are uncomfortable or confusing; at their worst they are serious life-altering events. By working through them we learn to try harder, practice longer, or to think things through, ultimately discovering that we may be stronger than we think; capable of handling events that initially seem overwhelming. Beyond the wrappings of change and the requirement of resolution, within each loss there lies an opportunity for learning.

3. Losses can form a personally tailored life-long curriculum. Despite their potential for learning, viewed through the wrong binoculars, losses are isolated despair-riddled destinations with no relationship to one another. Some childhood losses are predictable and universal, others are unique to an individual. In each lifetime, these generic and personal losses fall into a unique never-to-be-repeated sequence of events. For those who can appreciate their value, losses are an opportunity to learn via the world's most personally tailored curriculum.

In summary, childhood losses are critical learning opportunities that form a unique life-long curriculum. For each destination, there is something of value - a concept, a skill, an idea - to take along for use later down the road.

Children & Death

"And nothing except death is forever. Life is not forever. Being a kid is not forever. ... Death is really the only forever thing we face in life. ... But most religious people believe that death is not exactly forever."

In the last century, two books by Elizabeth Kübler-Ross initiated a shift in attitudes toward death and dying. Whereas parents prior to 1969 wondered *whether* to inform a child of a death and/or involve him/her in the funeral, by the late 1900's the question reverted to *how* to involve even very young children. In her first book, *On Death and Dying*, Kübler-Ross noted that:

...children who are allowed to stay at home where a fatality has stricken and are included in the talk, discussions, and fears gives them the feeling that they are not alone in the grief and gives them the comfort of shared responsibility and shared mourning. It prepares them gradually and helps them view death as part of life....
(1969, p. 20).

Grief in children assumes a variety of profiles that are dependent upon age, ability, and personality. For those of us who work with children with ASD, knowledge of what is "age-appropriate" can help us recognize the elements of a child's response that are *typical* of his or her chronological development. This section outlines how a child's perception of death changes with advancing years, and provides ideas for adults. In addition, it forms a frame of reference for guiding a child with ASD through loss - whether the death of a loved one or a day-to-day loss that the child *regards* as traumatic.



*From page 98 of *Lost & Found: A Kid's Book for Living through Loss* by Rabbi Marc Gellman and Monsignor Thomas Hartman (1999).



Infants, Toddlers, and Death

Little has been written about how infants respond to death. From birth to about ten months of age, it is believed that infants perceive death as an absence and a significant change in routine. An infant will be most impacted by the death of his or her central caregiver, responding to the new faces and changes with tears, loss of appetite, irritability, and difficulty sleeping. Following the death of a family member, those caring for an infant are advised to maintain the daily routine while minimizing the number of new faces, sounds, and events.

Beginning within a few months of the first birthday through two years, a toddler's response to death is different from that of an infant, and he or she will need adults to respond accordingly. By age two, children have an improved memory and a growing command of language, and readily sense and respond to the emotions of others. Despite these emerging skills, toddlers cannot conceptualize death or understand it. They often perceive the absence as temporary. As is the case with infants, adults can support toddlers by preserving and returning to the daily routine* and minimizing contacts with unfamiliar people. To explain death to a toddler, using direct and literally accurate phrases is recommended; for example, "Daddy no more."



Early Childhood and Death

For a child ages three to seven, the death of a loved one is potentially a very confusing "destination," eased by the thoughtful guidance of adults. No longer very little people with diapers and undefined personalities, young children are egocentric, curious, and literal in their interpretations. They can express a wide variety of feelings (love, anger, sorrow, grief-through-play). The perception that death is temporary is still a predominant theme. At this age a child's mind begins to separate reality

from fantasy, though may not yet be confident of the distinction. It is important for adults to describe their own feelings - this helps a young child learn via grownup example that it is okay to share negative information and emotions.

To explain death to a young child, experts advise adults to use clear, honest, literally-accurate information coupled with finely-tuned listening to keep track of a young child's level of understanding. It's important to dispel any perception that death is temporary. As described in the book, *Helping Children Cope with the Death of a Loved One* (Kroen, 1996), a child may be told that the person's body has *totally stopped* - no longer able to breathe, walk, eat, or sleep again - incorporating carefully selected vocabulary that supports a child's comprehension. For example, using the word *very* many times can reassure a child and help to give his/her fears some perspective:

...Tell them that people or animals usually die "when they are very, very, very, very old. Using multiple "very's" implies that most humans have a long life and live to an old age. Saying that people or animals usually die "when they are old" - without the "very's" - may be misleading. For preschoolers, a teenager is "old" and their parents and teachers are "very old." (p. 15)

Multiple "verys" are also helpful when distinguishing between someone who has died after being *very, very, very, very* sick, versus a classmate who is sick with a cold, compared to a friend who is *very sick* with the flu.

Young children characteristically ask questions - and learning of a death is no exception. Their inquiries are direct and to the point, lacking the social and emotional finesse of older children. In fact, beginning in early childhood (up to the age of nine) it is normal for a child to repeatedly ask the same questions about death (Kroen, p. 20). The book, *Your Grieving Child: Answers to Questions on Death and Dying* (Dodds, 2001), provides answers to frequently asked questions, making it a good resource for adults. Each child is unique, as is his/her ability to benefit from the

*At any age, returning to routines as soon as possible provides continuity between life before and after the death of a loved one.

information. Answers are only helpful when a child understands their content. For this reason, adults are advised to use unassuming questions to check for comprehension, for example, "What do you think about that?"

Beginning in early childhood, understanding of the following concepts increases: 1) death is forever; 2) death could happen to someone I know; 3) death could happen to me; 4) death means change; and 5) death means new feelings (Kroen, p. 18). Children add detail and improved understanding to these concepts as they mature.



Mid to Late Childhood and Death

As children mature from ages eight through twelve, their ability to appreciate the finality of death dramatically improves, as does their need to be actively involved in information and events. Equipped with significant cognition and social/emotional maturity, at this age a child knows his/her role within the family and can distinguish between fantasy and reality. Thus, the struggle is often *not* with understanding what death is, but with *acceptance* of the fact that a loved one has died. Grief may come and go in cycles, with the most difficult times coinciding with holidays and birthdays. Searching for the person who has died – often room to room – is normal at this age. Uncertain about what to do or say, peers often avoid a recently bereaved classmate, who in turn may try to hide his or her feelings. This can lead to feelings of anger as the bereaved child

blames the deceased for suddenly branding him as "different" among his peers. In an effort to "hold off" these and other feelings, children in this age group may be misinterpreted as cold or unmoved by the recent death in the family.

The death of a pet can be very traumatic for children. It is not unusual for a child to be far more distressed over the loss of a pet than that of an aunt, uncle, or grandparent. A child often has direct responsibility for the care and feeding of a pet, in other words, control of its well-being. In many cases, the child has had the opportunity to observe first-hand the entire life-span of the animal. When the pet dies, the inability to save that life, coupled with the loss of unconditional companionship that the pet provided, can be emotionally very difficult.

Experts advise informing (as soon as possible) and involving children in mid to late childhood when a death occurs. There are several resources that provide practical guidance. In general, an honest and supportive approach is best, with affirmation and acceptance of a child's feelings. Experts suggest giving choices, while encouraging expression of emotions through avenues that are comfortable and meaningful - whether the arts, a support group, or exploration of websites for bereaved children. The creative abilities and abstract thinking skills of children ages eight through twelve allow them to express their feelings through art; reviving and giving permanence to important memories. In addition, many children participate in support groups that provide the opportunity to meet other children in the same situation, and perhaps opportunities for new friendships. As is the case throughout a child's life, when adults share their own feelings it models an attitude that – though the child may wish to hide his or her feelings "in public" – it is safe to explore them at home.



Adolescence and Death

Adolescents have an understanding of death that is similar to adults; though emotionally they require careful guidance to accept a significant death and its implications as they work toward their own future as an adult. Able to think in abstract terms, with a detailed understanding of personal strengths and weaknesses, an adolescent still receives much of his emotional support from

others – adults and peers alike. An adolescent may experience sharp emotional contrasts, and fear the impact of the death on their plans to pursue their dreams and future plans. In contrast to children who may search their homes for the deceased, bereaved adolescents often search for the loved one outside of the home, usually in large crowds. Experts encourage adults to inform and include the adolescent in decisions surrounding a terminal illness and death.

while at the right time and place, including discussions of how the death will affect him or her personally. If an adolescent is not comfortable talking with parents, it is important to encourage contact with other adults, professionals, and/or peers who can provide support. As with infants, toddlers, school-age children, and adults, returning to typical routines, events, and social contacts with friends as soon as possible is important to working through a significant death.

Understanding grief in childhood is important for adults who work on behalf of children with ASD. As described in this section, typical children often exhibit responses to the loss of a loved one that are reminiscent of behaviors often attributed solely to autism:

- following a death in the family, a toddler may have a significant reaction to the changes in routine;
- a young child is likely to be literal in his/her interpretation of explanations of death;
- a bereaved child may repeatedly ask the same questions;
- a child may be more upset over the loss of a pet than an extended family member; and
- a grieving adolescent may appear self-absorbed or selfish, concerned about the impact the death will have on his/her plans.

In summary, understanding typical responses to grief helps parents and professionals accurately interpret what they observe in a child with ASD who loses a loved one, and places them in contact with new ideas (for example, using multiple "verbs" to accommodate for a child's literal perspective). This information "grounds" our discussion as the focus of this article expands in the following section to an exploration of the profile of loss - all losses - in children with ASD.

Loss and Children with ASD

**You can't decide to win, but you can decide to try to win.
You can't be sure that you'll win,
but you can be sure that you'll never give up.*

Children with ASD face a myriad of challenges as they encounter life's disappointments, and *loss* is at the center of many struggles. Sometimes, a loss is perceived *similar* to other children. For example, upon hearing that outdoor recess is cancelled due to rain, the child with ASD sighs in disappointment. Frequently, though, the child with ASD demonstrates a response that is similar in content to that of his peers - but different in its intensity; on other occasions his response may be *opposite* or *genuinely unique*. This section describes the typical, intense, and unique responses of children with ASD to loss.



Typical Responses to Loss

Adults are keenly aware of the potential impact of life's setbacks on a child with ASD. The distress that results from a subtle change in routine can cause parents to avoid activities that hold even the slightest potential for a tantrum, just as it can cause a creative teacher to become a defender of structure and predictability. In their efforts to "pave the way" to avoid intense collisions with loss, adults may prevent important opportunities for discovery and learning. In addition, a child's frequent and/or severe reactions to loss may be so pervasive that his or her *typical reactions* pass unnoticed by adults.



*From page 31 of *Lost & Found: A Kid's Book for Living Through Loss* by Rabbi Marc Gellman and Monsignor Thomas Hartman (1999).

Typical Responses to Day-to-Day Losses Children with ASD are, most of all, children with personalities, talents, and abilities. In their repertoire are typical reactions to loss. Harrison is eight years old, diagnosed with ASD. There was a Yo-Yo™ demonstration and assembly at his school followed by a predictably popular Yo-Yo sale. Like many of the other students, Harrison was excited about purchasing a Yo-Yo, but unfortunately they sold out. This required some students to wait until more arrived. Harrison was disappointed, but cooperated with the plan. He is not the only student to demonstrate a typical response to a day-to-day loss. In the words of children with ASD:

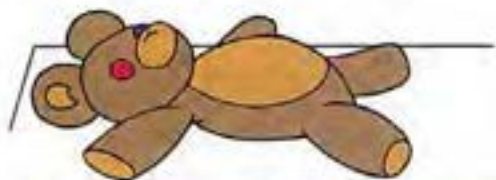
- *Changing from public to home schooling, I lost a great teacher and a chance to see if I can make friends.*
- *I hate losing at board games, but I try not to throw the cards and everything.*
- *I really would rather win. It just feels better.*
- *It confused me when my friend started sitting with other kids at lunch.*

Typical Responses to Death & Dying Little has been written about grief and children with ASD. Diane C. Rawlings (2000) studied 16 bereaved adults with ASD in residential settings in the United Kingdom, and concluded that some clients demonstrated a range of typical grief reactions in response to the death of a family member or close associate. This is consistent with many of the email messages that I received from parents and professionals, indicating that bereaved children with ASD often have responses to death that are typical of the curiosity, concern, and compassion demonstrated by their peers. Consider the typical elements of the following accounts:

- *My son is 4 years old. He had a lot of questions that I was not expecting: What color are you when you die? Why do they bury you? Won't you get dirty? When I am dead, will you miss me?*
- *After Aunt Grace died, Blake asked the same questions over and over.*
- *In response to learning that his step-grandfather had died of cancer that morning, my son Jerrad, age eight, said, "Mom, I will take care of you."*
- *When Jesse died of leukemia, we told Andrew, at age 8, right away. Andrew searched room by room. I thought he didn't understand, but he did - returning to me very upset.*
- *Upon hearing of his grandfather's death, Daren, age 17, said, "I just lost my best friend."*

By documenting the curiosity of children like Blake, the concern demonstrated by Jesse, and the compassion of Jerrad ("Mom, I will take care of you.") we are reminded of the typical responses to death that children with ASD can demonstrate.

Could it be that the typical element of a child's response may be overshadowed by its atypical qualities? For example, Andrea is 10 years old and has Asperger's Syndrome. Her sister, Bobbie, was killed in a car accident. Upon hearing the news, Andrea said, "No, that can't be," and returned to reading her book. Her words were "emotionally flat." What Andrea said reflects the struggle with acceptance often demonstrated by many children her age. The absence of tears or any noticeable distress misled her parents to conclude that, "Well...Andrea is all set;" as they turned their focus to their own grief and funeral arrangements. A few weeks later Andrea was assigned an essay at school. She wrote about her sister's death. The content of Andrea's essay took her parents by surprise. Andrea expressed genuine feelings of loss and confusion. To acknowledge and respond to the typical elements of the response of a child with ASD - even those that may come disguised in part as "autistic behaviors" - is to recognize an opportunity to be an important part of a child's healing, learning, and emotional growth.



Intense Responses to Loss

Children with ASD often react to life's experiences in a typical manner, but their responses may be magnified in intensity or frequency.

Intense Responses to Day-to-Day Losses There is often a sharp contrast between the reaction of a child with ASD to a day-to-day loss and that of his or her peers. The missing puzzle piece that elicits frustration and a few tears from a typical child may throw a child with ASD into inconsolable despair. The lost stuffed animal that causes a typical six year old child to "hold back tears" while launching a focused search of the play room, could result in the full

retreat of the child with ASD to a world of solitary sorrow. Being a member of the losing soccer team is disappointing to a typical third grader, but may be an intolerable outcome capable of “de-railing” the rest of the day for a child with ASD.

Parents and professionals have shared other examples of intense responses to day-to-day losses demonstrated by children with ASD, including:

- *My son Max (3 years old) gets intensely emotional about balloons that he has released and are now stuck in the trees in our yard. EVERY time we pull into the driveway, he points to the balloons stuck in the tree and cries “Balloon, Balloon.” He is very upset at the trapped balloons, yet he still releases them.*
- *When Christopher, age 7, loses anything – scissors, papers, a marker – he needs to find it immediately or he panics. If I tell him to wait a second, he just can’t.*
- *Tiffany, age 8, and her brothers and sisters love Cara, their babysitter of several years. However, to this day Tiffany cries inconsolably for several minutes when her parents leave to go out for the evening. Within fifteen minutes, Tiffany is calm once again.*

Intense Responses to Death & Dying Children with ASD may demonstrate responses to death that are exaggerated in comparison to their peers. Their responses, though typical in topic or format, may be characterized by an increased or decreased intensity of emotion, endless repetition, and/or seemingly timeless duration.

One striking example of an intense response to bereavement is described by Rita Jordan and Stuart Powell in the chapter *Emotional Aspects of Development*, in *Understanding and Teaching Children with Autism* (1995). At 10 years of age, Frank, a boy with autism, communicated largely with a signed vocabulary of 150 words. Aside from “rough and tumble” sessions with his father after school each day, Frank stayed to himself during free time. One day while Frank was at school his father died of a heart attack. Frank was placed in respite care. Frank was told of his father’s death when he returned home after the funeral. It was unclear how much Frank understood. A little later, as the time for the daily rough and tumble session passed, Frank became distressed, kicking and banging amidst signing for his father. Frank ran to his father’s closet (wardrobe), only to discover all of his father’s clothes had been cleared away:

He then cried inconsolably as he swung the wardrobe door to and fro. This behaviour lasted for some hours and it was only with some difficulty that Frank was persuaded to have something to eat and go to bed. On waking in the morning, his first action was to return to his father’s wardrobe and continue his wailing and swinging on the door. He could not be persuaded to go to school in the taxi and in desperation his mother phoned the school for help (p. 48).

Explanations of his father’s death seemed to have little impact. Each day as the time for rough and tumble play passed, Frank would return to his father’s wardrobe and repeat the behaviors. The situation was resolved when a school social worker engaged Frank in rough and tumble play for a few weeks, “filling” the void of loss that was the most meaningful for Frank. This approach is described in the article by Rawlings (2000), mentioned earlier:

It is likely that the loss of a significant person through death creates anxieties and difficulties for the person with autism because of the loss of the functions that the deceased person performed for them. Finding others to replace the deceased in terms of the activities that were shared and the needs that the deceased met might be a way of addressing the loss (p. 26)

For Frank, the rough-housing each afternoon with the social worker - initially at home, and later at school toward the end of the school day - helped to fill an initial void as Frank learned to adjust to the death and absence of his father.

Parents and professionals working on behalf of children with ASD share anecdotes of other intense reactions to the death of a loved one:

- *My son gets obsessed with the process of death and violent acts. When I try to explain death to him, he becomes so obsessed with it that it is the only thing he will talk about. ...Once he starts talking about the subject, he just will not quit! Maybe he takes some kind of comfort in knowing exactly what our answers will be, but it is really annoying.*

- *Dustin's father passed away six years ago. Since then, he's been playing funeral procession - cars lined up perfectly, Dad's in the car in the front. He's 10 now; the funeral procession is repositioned each day.*
- *My husband's friend died very unexpectedly a few months ago. My son constantly still asks questions about it. He seems to be trying to hurt his daddy's feelings.*

Although it is typical for a child to ask questions, initially refuse death's finality, and/or use play to re-enact events surrounding a death, the intense and/or persistent quality of these responses can place additional pressure on those who are seeking to "move on" after the death of a family member or friend. Increasingly, other family members are irritated or frustrated by the unending repetition or unfaltering themes. As one widow concluded, "We live on a farm. I used to wish my son would develop some interest *other than Thomas the Tank Engine™*. That is, until my husband was killed in a harvesting accident. William's interest turned to farming machinery. I try to be patient, but it's emotionally difficult for me to keep answering Will's endless questions about tractors and cultivators."



Unique Responses to Loss

There are occasions where the responses of the child with ASD are *unique* in contrast to our own experience. For example, as brothers and sisters are delighted at the announcement of the cancellation of school due to a "snow day", the child with ASD may be simultaneously thrust into the grips of despair over the loss of the daily routine. Then there are the concepts, like *sharing and turn-taking* - that hold inherent valuable returns and social gains for most of us - that can represent absolute loss to the child with ASD. At other times, a child with ASD may demonstrate a reaction that is disarmingly out of context, for example, displaying no emotion in response to the news of loss of a loved one or laughing at a funeral. All of this makes *Unique Responses to Loss* a category with extensive variety and plenty of anecdotes that reflect the many individual profiles of children with ASD.

Unique Responses to Day-to-Day Losses Ask any parent of a child with ASD to describe their child's unique responses to day-to-day losses and their stories will fill an afternoon. Speech and language pathologists, psychologists, teachers, and assistants also have anecdotes to share. From the files of parents and professionals, we pull these examples of unique responses to day-to-day losses observed in children with ASD:

- *While other students on his spelling bee team rejoiced over their win, my student, Adam, was thrust into the grips of despair because the final contestant - for some unknown reason - chose not to stand as she spelled the winning word.*
- *Walking with the family under a footbridge on a sunny day, our daughter, Jenna, began to cry inconsolably over the disappearance of her shadow, despite our efforts to explain what had happened. She simply would not move. Once she calmed down, we emerged into the sunlight on the other side. Upon being reunited with her shadow, Jenna jumped and bolted frantically in an attempt to detach from it. Later, she told us that she wanted to just "...keep it under the bridge" so she would not lose it again.*
- *Parker is seven. He told his teacher he wanted to be an airline pilot. When she inquired as to why, he said, "So I can retrieve my kite." It's a paper kite that he lost over two years ago.*

Information can bring understanding to that which seems confusing and unique. After a discussion of some of the unique responses to death and dying, we'll look at theories that may help to explain the statements and behaviors that take us by surprise.

Unique Responses to Death & Dying The unique responses to death and dying that we see in children with ASD are highly varied - with some common threads. Dr. Tony Attwood, a noted international expert on autism spectrum disorders, has shared that children with ASD may not experience death like the rest of the family or his/her peers (Attwood, 2002). The intensity of their responses may be more or less than others, or unique and unexpected. Though the focus of this article is on loss and children with ASD, it is adults with ASD who are able to provide us with the most accurate insights into their perceptions of the events and emotions surrounding a death. The contrasts in their experiences - from those who report extreme sorrow and grief to those who feel "nothing" - define the opposite

ends of a spectrum of grief reactions. Regardless of the presence or absence of feelings of loss or sorrow, a common thread of confusion is a prevailing theme that runs through their experiences.

Jennifer, a young woman with Asperger's Syndrome, describes how she was overcome with emotion when her mother died. The planning of the funeral rested largely on her shoulders, and this added to her emotional turmoil. She was upset to learn after the fact that some of her decisions had shocked her family and friends. Apparently, for some funeral arrangements like the acceptance of flowers or memorial contributions, it was most important to consider the wishes of the *person who died*; whereas other decisions seemed to ride on arbitrary, unspoken, but nonetheless critically important expectations. How was Jennifer to know whose wishes prevailed with each decision? Jennifer also had difficulty expressing her grief, and friends and family had an equal challenge recognizing it. The misunderstandings that ensued caused others to mistakenly conclude that Jennifer was largely insensitive and uncaring toward her mother's death. They could not have been more wrong.

Other adults with ASD share that they do not feel grief. Their perspective is dominated by logic and face-value assessments. This is evident in the following excerpt, written by a man with Asperger's Syndrome, 58 years of age:

I am more attentive to the deterioration of my parents than are my siblings, to the extent of personally caring for their personal and physical needs in my home. When they pass, I experience NO sense of loss. ...It's right for me to care for the ones who raised me. What evokes the indignation of others is my stoicism about death. It's not emotional. When they are gone (father already, mother soon), I'll go on as before with no sense of loss. What's the big deal?

Similarly, Edgar Schneider, who has autism and is the author of *Discovering My Autism* (1999), writes that "Never in my life have I ever felt grief, or even a sense of loss" (p. 51). His mother passed away prior to his diagnosis of autism, while everyone else in the family expressed grief and sorrow:

I felt nothing. I also felt that there was something wrong there. Somewhat sardonically, I said to my pastor (who had been a psychologist before becoming a priest), "There are all kinds of support groups for people who grieve, but nothing for people who should be grieving but don't" (p. 51).

Whether severely impacted by the loss of a loved one, or absent of sorrow or grief, the comments of these adults with ASD reflect apprehension in socially "getting it right" or understanding the comments, reactions, and emotions of others. Edgar Schneider felt this confusion as a child: *Someone in my family, quite elderly, had just died. I found the ensuing consternation on everyone's part very discomforting. That was, mostly, because I did not know what caused this climate of great agitation (Remember... uncertainty was my biggest source of fear.)* (p. 53).

Following the death of a loved one, parents and professionals may also be confused by the seemingly "odd" or unexpected comments and behaviors of children with ASD. When there is a death, adults are at the height of their own emotions - at a point where they may be unprepared or ill-equipped to effectively handle the unique interactions that take them by surprise. In the following example, a child's confusion matter-of-factly runs head on into the emotional status of his surroundings, subsequently overwhelming his parents:

A close personal friend to both my husband and I died of a heart attack. We decided to include Davis, our son with Asperger's Syndrome, in the experience of the funeral home visitation. At the funeral home, several people were gathered around the casket. One woman commented, "What a terrible shock this is." Davis announced, "SHOCKED? Why are you shocked? Lots of people who smoke die of heart attacks." The group exchanged awkward glances. I quickly escorted Davis to the lobby. He thought the adults were astoundingly uninformed as to the risks of smoking cigarettes. Overwhelmed by the loss of our personal friend, Davis' comments added pressure to a situation that already was difficult.

In summary, children with ASD may demonstrate responses to loss that are similar to their peers, intense in comparison, or unique. Sometimes, one element of a child's reaction may be typical for his or her chronological age - but the intended meaning may be overshadowed by unique factors. In other instances, a child's response may seem to occur "out-of-the-blue" and/or out of proportion in intensity to the problem at hand. Why the difference?

Appreciating the Differences

*"We believe that overcoming loss
is possible for everyone, but it is not
possible for everyone at the same speed."*

What accounts for the intense - and sometimes unique - responses of a child with ASD to loss? Many of the stories and anecdotes in this article reflect the importance of quickly and accurately assessing a social event: recalling a past experience or experiences that may be currently helpful; sequencing that information in terms of importance and priority; determining what other people know or feel in that context and putting it all together to know what to say and do next. "A typical person can accomplish this almost 'without thinking.'" Most of us have lost keys, competitions, mittens, games, and tickets. These experiences are cataloged and filed for later reference. The ability to pull up relevant experience and information, sequence it in terms of time, place, and feasibility, or identify those that can help us if we fail, plays a

big part in finding a lost item, or processing the loss of a pet or person. To a child who struggles with the identification and organization of relevant information, lost items present themselves not as irritating - and somewhat anticipated events, but instead as sharp and permanent assaults on an otherwise perfect present tense. Thus, the difference in the response of a typical person to loss, and that of a person with ASD, plays out on different social landscapes.

People who are typical have the ability to rapidly assess and interpret social context. Context is not simply an understanding of "where;" it is, in fact, the ability "get the gist" via the simultaneous identification, collection, interpretation and application of a multitude of factors that include but are not limited to place, age, emotion, gender, objects, time, and season. This is what Uta Frith calls *central coherence* (Happé, 1995). In this case, *central* may be an understatement. In terms of social-communication, context is "central" as the sun is to the planets; the *spindle* in social-communication around which meaning revolves. And it is here that the resulting intent, purpose, and social insight of human communication - often the entire meaning - can elude the person with ASD.

Day-to-day losses rarely take us by surprise - in a way, we expect to lose the keys to the car. We base that expectation on the 150 times before when we've misplaced the car keys or similar items, in similar situations. Noticing that the keys are missing, we're a little confused but definitely not shocked. In a flash we've retrieved and sequenced all that we've learned from missing keys before. *We know that sometimes things get lost* and, before we even move, our mind has narrowed the search to "...the last time I used them" and consequently "...the first place I might look." Referred to as Executive Function (Russell, 1997), we have an efficient "cognitive team" that pulls the file folders we need and selects and prioritizes the most probable routes to a solution. We go to the one person most likely to have information - or the temperament! - to effectively assist us. Enter *Theory of Mind*.

Theory of Mind (Baron-Cohen, Tager-Flusberg, & Cohen, 1993) is our ability to make very accurate guesses about what the people around us know, feel, or believe. In a search for lost keys, we "automatically" know who may have seen our keys (for example, that person who cleaned the house yesterday, or was with us the last time we used them). If we were alone when we misplaced them, we recruit help from the most intelligent or emotionally calm person that is available. Theory of Mind is also critically important when someone has died: we know who may not



*From *A Word to Adults about this Book*, in *Lost & Found: A Kid's Book for Living Through Loss* by Rabbi Marc Gellman and Monsignor Thomas Hartman (1999).

**In the last decade, a wealth of new information has helped us appreciate the cognitive differences of children with ASD. Beyond the reach of this article, the reader is encouraged to learn more from the wide variety of resources that are available.

have had access to information about the death; who to go to for assistance with funeral arrangements; and who to seek out for emotional support. Knowing what other people know, and the ability to recall the past emotional and social experiences that are relevant to the current circumstances, helps us quickly and efficiently share information, while placing us in contact with those who can support and assist us.

From a typical social perspective it is all so obvious and easy - largely because central coherence, executive function, and theory of mind are the ultimate in team players. Their efforts may overlap, but they never override one another.

In contrast, a child with ASD may react to a loss with the shock of an unexpected assault. With impairments in central coherence, executive function, and theory of mind, a loss potentially *is* a shock which the child is unequipped to handle on his own. We begin to walk to "the last place I saw those keys" while the child with ASD is under siege, stuck in the grip of *The Keys Are Gone*. Unable to independently retrieve relevant information, there is little to ease his loss or temper his mood. Severely challenged in launching searches of his own, the child is unable to imagine that others *know* how to find things or have these skills. From his perspective, our reassurances to relax because, "*The lost keys will probably be found...*" holds little truth, just as there is no reasonable explanation for our relative calm. The car keys have vanished - we're moving toward a solution and the child with ASD is stopped in his tracks. Period. In terms of a terminal illness or death, the challenge is similar, but coupled with unfamiliar events and emotions that are likely to be overwhelming. The foreign contexts, faces, rules and routines exponentially increase the likelihood for social mistakes. A child's comments - or literal interpretations of the explanations of adults - may reflect his or her challenges in identifying the intent, purpose, or "gist" of a conversation or social setting. The social and emotional errors may upset those who do not understand autism, while simultaneously making those who *do* know about autism very proud of what the child *gets right* in spite of the difficult circumstances.

Work on this article has led to a theory that a child with ASD may perceive and experience traumatic losses far more frequently than his or her typical peers, and a question as to how this may impact his or her social and emotional development. Children with ASD often encounter surroundings where people come and go without reason and objects disappear without hope of retrieval. In the midst of their confusion, the adults that surround them come to the totally out-of-context conclusion that "...there is nothing to be upset about." Where is it that a child with ASD will learn trust and discover the value of social connections? Like any theory, this one raises additional questions:

- Is it possible to be sensitive to the perspective of those with ASD without losing our own routines and need for peace and predictability in the process?
- If we can't determine why the child is so upset, is there any way to console or help him regain the calm that enables problem-solving?
- With all the possible losses that arise in the life of a child with ASD - with some of them centering around topics that challenge our own ideas of what is important and what is not - is it possible to negotiate a reasonable route to a solution that enables parents and children to work together, comfortably, toward a solution?

There are no easy answers to these questions, but for every travel destination there's a guide book. When it comes to teaching a child with ASD about loss, a "guide book" includes all that brings *meaning* to the efforts and explanations of parents and professionals. It translates abstract concepts into their tangible counterparts - giving elusive ideas a workable frame, lining up isolated events so they may be logically linked, affirming emotions without assuming what they should be - to guide children with ASD toward practical and positive control of their own experience. The last decade has seen the development of a wealth of creative, visually-based materials and strategies (Attwood, 1998; Faherty, 2000; Gray, 2000; Hodgdon, 1995; McAfee, 2002; Prizant et al., 2002; Scopler & Mesibov, 1995; Sussman, 1999; Quill, 1995; Winner, 2002). These resources make the necessary accommodations to support learning. In addition, they share a commitment to patient and positive one-step-at-a-time instruction. The final "destination" of this article follows suit with new guidelines to help children with ASD learn from loss.

Guiding Children with ASD through Loss

**Patience with grief and loss is essential to realizing wisdom and compassion.*

As a parent or professional, you probably recognize aspects of your own experience in many of the anecdotes in the previous sections. What is challenging about loss and children with ASD is that it can take us on a journey of unanticipated on-the-run decisions and emotionally uncomfortable destinations. If losses would announce themselves in advance, we'd be ready for them. Unfortunately, this is not the case. It requires us to "expect the unexpected" in even the most ordinary circumstances. Since each child with ASD responds to loss from his or her individual and sometimes unique point of view, a "recipe" approach to intervention is likely to be ineffective. Instead, guidelines can help us turn life's losses into learning opportunities.

Toward that end, the following *Guidelines to Teaching Children with ASD About Loss* are submitted:

1. **Abandon Assumptions** in favor of respecting the child's perspective and following his or her lead, while making an effort to provide...
2. **Advance Notice** that includes information a child may be missing, adding meaning with...
3. **Accommodations and Analogies** that build concepts and...
4. **Affirm Feelings**, to make meaningful and effective...
5. **Associations** between related past, present, and future experiences.

Collectively these guidelines help children "move through" uncomfortable destinations, to view them as *temporary* circumstances and learning opportunities. This section describes the practical application of each of these guidelines.



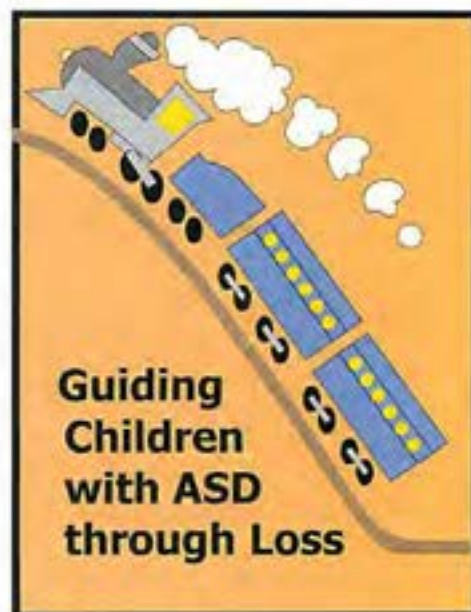
Abandon Assumptions

To *Abandon Assumptions* is to "start from social scratch" - replacing our confidence in interpreting the behavior of a child with ASD with respect for the differences. It's the practical application of considering an event alongside what we know about how that child perceives the social world. Specifically looking at loss, we have preconceived notions of what should, and should not, be considered a loss. Abandoning assumptions to regard losses from a broader perspective helps us respond to what a child *needs*. It pulls our attention away from the (sometimes seemingly insignificant!) *topic* of a loss, to the emotions that surround it.

Many people mistakenly believe that *all* children are work from the same set of social information. From this point of view, a child's intense response to the loss of a toy is viewed simply as *inappropriate behavior*; or in the case of the death of a loved one, a child's stoic exterior is hastily interpreted as disinterest or a lack of compassion. This may or may not be the case. Faced with an adult firmly planted in this type of social belief system, the assumptions that surround him or her are tight and restricting, like shadows cast at high noon. Consider the following statements, with their possible underlying assumptions listed in parentheses:

- "Shhhhhhh. There's no reason to be upset." (*You are wrong or in error to be upset.*)
- "You're just missing a little red Lego™ block? Use that white one instead!" (*Your product or your preference is not important.*)
- "Edith doesn't seem upset at Grandpa's death." (*Edith's reaction is wrong, she does not care.*)

*From A Word to Adults about this Book, in *Lost & Found: A Kid's Book for Living Through Loss* by Rabbi Marc Gellman and Monsignor Thomas Hartman (1999).



Parents and professionals who learn to abandon assumptions, also notice a marked decrease in the inappropriate behaviors of children with autism. Those behaviors may still occur, but they are less frequently *inappropriate* when viewed with respect for the child's point of view. The result is a new - more careful - *Search for Inappropriate Behavior* that is less frequently successful because - according to the dictionary - to be considered "inappropriate" a behavior has to be "not suitable" or "not proper" (Oxford University Press, 1999). If a child is missing social information that others have access to (theory of mind, central coherence), and/or is responding according to his perception of an event, at times she or he *may not be aware of what is or is not socially suitable or proper*. How can one possibly conclude a behavior is inappropriate, without looking further to our responsibility in sharing information that would make new, more effective responses logical?

Abandoning Assumptions Regarding Day-to-Day Losses In practice among day-to-day losses, to abandon assumptions requires adults to look from a broader, bigger-than-the-inconvenience-of-the-moment perspective. According to the authors of *Lost & Found*, losing a block or another toy is important to any child, and:

It's okay to be upset about losing stuff. Some people may tell you that things don't matter. They may tell you that it's wrong to be so attached to your stuff, and that if you lose it, it's no big deal. We don't think that's true. Some things matter because they are tools. ...When you lose your tools, life gets harder and definitely less fun (Gellman & Hartman, 1999, pp 20-21).

Admittedly, it's difficult for a parent to abandon the task of making dinner when drafted into a child's search of the play room for one tiny block; lost blocks come and go attached to incredible waves of inconvenience. If this is *just a lost block*, the goal is only to find it so the day can continue. But looking beyond that assumption a lost block can become a learning opportunity. The goal is to teach the child, one step and loss at a time, to develop strategies to find life's "blocks" in the future. The value lies not in the dollars and cents or physical size of the block, but in learning to work through loss and discovering alternate solutions. Abandoning assumptions, it is so much easier to leave the task of making dinner in the kitchen for a learning opportunity, than it is to simply recover that which is lost.

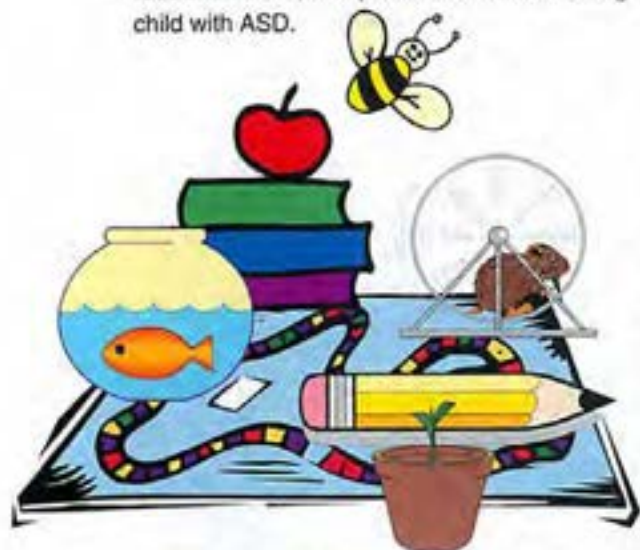


Abandoning Assumptions Related to Death & Dying To abandon assumptions when a death occurs requires us to be alert to the pitfalls that may cloud an accurate interpretation of the child's reaction. Instead of harboring a preconceived notion of what his or her response *should be*, the focus is on helping the child identify and work through his or her own perceptions and feelings. As we've discovered, some children with ASD may respond to the death of a family member with comments that are disarmingly factual and/or emotionally out of context. For others, death is the ultimate change; not solely the loss of a loved one, but much more. Some aspects of a child's response may be entirely typical, within age norms, or the meaning of a child's words may be hidden by his or her difficulty matching them to the expected or typical feelings and pragmatics.

Considering the emotional status of other family members and friends, it isn't easy to abandon assumptions when a loved one has died. The tendency may be to try to "coach" a traditional response that the child may not be able to relate to, or understand, which could add to his or her confusion. Indeed, the child with ASD may not understand the feelings of others, and this may require as much - or more - explanation than that of the illness and death itself. If a child does not feel emotions that are in sync with friends or other members of the family, he or she will need information about why everyone's behavior is suddenly so different and when - and how - things will return to "normal". Replacing our assumptions with an accurate understanding of typical behavior - and an appreciation of the exponentially increased challenges that a child with ASD may encounter following a death - makes the rest of our role as parents and professionals in these difficult situations a little easier.

*Interestingly, *inappropriate* follows the words *approachable* (friendly, easy to talk to) and *approbation* (approval) in the dictionary.

With social assumptions out of the way, the subsequent steps of providing advance notice, making accommodations, and affirming a child's experience, while building associations among past, present, and future experiences becomes so much easier and actually quite logical. A final word of caution, though: respecting and affirming a child's point of view does not grant him or her permission to call all of the shots throughout the day, rearrange the living room furniture linearly, or assume possession of the deed to the family home and the life of all those within it. It will, however, build meaning into more interactions, visually enhance additional concepts, demonstrate effective conflict resolution skills, and place a value on learning in place of the avoidance - or disdain for - the losses encountered by a child with ASD.



Advance Notice

Advance Notice is having information before it is needed. For those of us working with children with ASD - where we expect the unexpected - we've discovered the value of being prepared for future issues. Children with ASD also benefit from advance notice. Over the last decade Social Stories™ have provided them with a wealth of social information. Thus, *Advance Notice* applies to all of us; as one team. In this matter of loss, we can gather the background information we will need, use Social Stories to share what we've learned with the children in our care, and incorporate other ideas and activities that collectively work to provide the benefit of knowledge, and knowing what to do ahead of time.

Books for Adults and Children Some people say that knowledge is power; I think it's an unsung hero. In my career I have observed knowledge at work first-hand many times, and it's a striking comparison to those times when it doesn't seem to be present. There are wonderful books for adults and children that can build our confidence regarding what to say or do when loss is part of the picture. *Lost & Found*, mentioned and quoted throughout this article, is helpful for both adults and children. For adults, it will increase our awareness of the many kinds of loss that children encounter each day, increasing the number of opportunities to teach children to work through them. Or, should the phone ring with news that Grandpa has died, we can have a book on the shelf to guide us. For children in mid-to-late elementary grades, *Lost & Found* is an informative and unassuming friend, a practical source of winning attitudes and problem-solving strategies. There are numerous other books, too. Many are reviewed and listed in Appendix A: Related Resources for Adults & Children. Knowledge - or just knowing where the knowledge we need is located - is a great place to start.



Social Stories and Loss Just as books provide a wonderful base of information, *Social Stories*™ can personalize information and focus on topics addressed nowhere else in children's literature. A Social Story is a short story, written in a special style and format consistent with the learning characteristics of children with ASD, that describes a concept, skill, or activity. Social Stories inform, describe, and reassure with an overall patient and unassuming quality, making them welcome as messengers for over a decade. They are perhaps at their best when presented in advance of new or potentially troublesome events. Social Stories can play a big role in sharing information about loss.



Social Stories about loss are likely to be difficult to write. As we sit down to write Social Stories about loss we may get... *STUCK*. Equipped with paper and pencil, the pencil doesn't move. Using the computer doesn't help because words don't appear on the screen either. Even those of us with plenty of experience are likely to be overwhelmed.

**Lost & Found* may be difficult to find. A limited number of copies are available from The Gray Center for Social Learning and Understanding. www.TheGrayCenter.org

There are so many possible topics and so many abstract concepts! For example, when it comes to death and dying, there are many activities to introduce, perspectives to consider, and feelings to describe. Sometimes, simple modifications in format, content, and/or selection of vocabulary can make Social Stories about loss easier for adults to write and easier for children to understand. Before sitting down to write a Social Story about loss, you may want to refer to Appendix B: Social Stories & Loss / *Writing Social Stories about Loss*. There you will find a few hints and ideas to help get the words on the paper.

Advance Notice about Day-to-Day Losses In a way, having information about loss - and consequently an increased awareness of its potential - may *add* to our confusion. In terms of the numerous day-to-day losses, how is it possible to prepare children in advance for every loss they may encounter? Even if it were possible to set the stage ahead of time, considering the rather long list of losses that may occur, a child may decide to stay put or return to bed. Similarly, if a teacher were to preface each assignment with a forewarning of looming educational doom: "Now, remember class, you may *fail* as you attempt to complete this - but, just remember, losing is a learning opportunity!" students may be more discouraged than encouraged. The goal is not to anticipate *each and every* loss - it is to maximize the learning opportunity of a *few*, by identifying those that are most likely or important, providing information about the possibility of one of two outcomes (success now or possibly next time), and effectively harnessing their educational potential.

In the past, the phrase "teachable moment" has been used to refer to potential lessons that arise in the course of other daily activities. The problem with the phrase, "teachable moment" is that it places emphasis on half of the educational equation, the *teacher*, who is presented with more things that he or she can teach. For our purposes here, the emphasis is on the *learner*, and *teachable moments* will be referred to as *learning opportunities*. Specifically in terms of loss and children with ASD, a *learning opportunity* is a setback which arises unexpectedly; is recognized by an adult, and creatively harnessed to lead to a new discovery; or an activity sensitively engineered to teach a child about loss and learning within a comfortable one-step-at-a-time structure. Here are a few examples:

- Board games based on luck, with adults modeling good sportsmanship and positive responses to loss.
- Pre-arranging cards in childhood board games, like Candy Land™ (Hasbro, 2001) to create situations and control their frequency, with the adult "going first" to model effective responses (adult is initially behind, then child is behind; adult gets sent back to a square at the beginning, child gets sent back similarly; adult is winning, child is winning; etc.). This can be tailored to game situations which are difficult for an individual child and controlled in line with his/her emotion regulation abilities and weaknesses.
- Frequent *mention* of adult mistakes and losses at home and on the job, the feelings associated with them, the steps used to resolve them, and new ideas discovered in the process.
- Recruiting the assistance of a child with ASD in looking for a lost item belonging to *another member of the family*, explaining the logic behind the search and assigning a specific task to the child with a defined ending, "Please look to see if the lost black shoe is in the bottom of the front closet, then report to me."
- Engaging in an activity that is easy for the child with ASD and difficult for mom and/or dad, who model strategies for handling their limited skills and the frustration or feelings of inadequacy that result. This may revolve around a child's area of interest, making it fun for a child to have others join his or her "agenda."



Advance Notice about Death and Dying Though we may hesitate to inform a child about the death of a pet or a person, chances are he or she has experienced death already. Whether the child *learned* anything about death from those experiences is up to us. Dying, and death, is part of a *life cycle*, and in that way it is somewhat predictable. From a very young age, children have a series of first-hand experiences with life and death, often with lives entrusted to their immediate care: a bean plant in preschool; insects in jars with mesh lids; fish in bowls; a hamster.





The bean plant, the bugs, the fish, and the hamster are real-world warehouses of important learning opportunities. While the bean plant is alive and thriving, we can mention how it drinks water, eats plant food, breathes air, grows and moves - laying the groundwork for a future explanation of how the *dead* bean plant *does not drink, eat, grow, breathe, or move* anymore. When the fish is alive and thriving, we can mention how it drinks, eats, breathes, and moves - laying the groundwork for a future explanation of how the *dead* fish *does not drink, eat, grow, breathe, or move* anymore. The hamster and all the pets to follow in succession hold the same, predictable, repetitive lesson - with the observable addition of sleeping - paving the way for our explanation that Grandpa or Grandma has died, and will not be able to drink, eat, breathe, grow, move, or *sleep* anymore.



Advance notice also applies to human illnesses and death. Experts advise that soon after learning of a serious illness, accident, or death, children - even those who are very young - should be told. A serious illness brings big changes to the daily and weekly routine, and to members of the family and their feelings. New people arrive, familiar people leave. Suddenly, Mom may be gone each weekend or Dad might seem unusually serious or preoccupied. There could be visitations to the hospital or funeral home, or attendance at a wake or a funeral. Explaining the emotions of others, providing structured opportunities for a child to help, and emphasizing the temporary nature of these changes compliments a child's intelligence, confirms the many changes, and provides some predictability to a potentially overwhelming situation.

Abandoning assumptions and providing advance notice can minimize the jolt of a daily loss, and explain and support a child's understanding and role in the death of a family member or friend, but only if the information has meaning for the child with ASD. Blending information with a *meaningful delivery* can improve the odds that the child will find a purpose or practical application for it. For a child with ASD, accommodating his/her cognitive strengths and weaknesses can translate an irritating interaction into a comprehensible conversation. Accommodations tie meaning to spoken words and text and minimize misunderstanding or unfortunate (though memorable!) social mistakes. In the same way, an effective analogy can provide a shortcut to genuine understanding. The following section, *Accommodations and Analogies* shares strategies to help us meaningfully guide children with ASD through loss, toward learning.



Accommodations in Vocabulary and Analogies

The use of accommodations and analogies to support learning is a *continual process* that involves a practical understanding of the information to be shared, coupled with an appreciation of the eyes, ears, and mind that are to receive it. The art of teaching children with ASD- *especially abstract concepts like those surrounding loss* - lies in the individually tailored use of materials and strategies to infuse meaning into instruction. All children learn best when they feel comfortable in an environment and capable of succeeding with the task at hand. Additionally, children with ASD benefit when: 1) activities and their role within them are structured; 2) visual materials are used to enhance meaning; and 3) instruction is related to personal experiences or interests. Many of us routinely make these accommodations. This section explores two additional

accommodations that are very important, *especially in light of the concepts and skills related to loss*. They are 1) careful selection of vocabulary and 2) the use of analogies to help us translate abstract concepts into their tangible counterparts.

Selection of Clear Vocabulary For a child who interprets words *literally*, at face value without the benefit of their intended meanings, the risk of expressive and receptive misunderstanding runs high. Where loss is concerned, it is exceptionally important for us to make a concerted effort to carefully choose our vocabulary and be extra cautious of all literal interpretations. The result is that we have to be more *sincere* than we typically are, making sure that our words match our intended meaning, our pragmatics, and the current context. The challenge also goes a step further. Some words have meanings based on observable, concrete information *and also* meanings that are rooted in cognitive theories (like our ability to take the perspective of others, theory of mind, and/or central coherence). Naturally, children with ASD are likely to gravitate toward those meanings that are *observable and concrete* over those requiring an understanding of *how people think or feel*. Unfortunately, much of our social information - and many of our social solutions - lie in the more "socially-based" meanings of words. This is true as we consider the word, *lose*, and other words related to loss, and the implications of the meanings we choose to emphasize when we are interacting with a child with ASD.

Vocabulary and Day-to-Day Losses The word *lose* has several meanings, some of them far more "concrete" than others. When we refer to an *item* as *lost* (past tense of *lose*), our emphasis is placed *on the item*. In the dictionary, the definition of *lose* begins with this meaning: "...1) ...to be deprived of or cease to have, esp. by negligence or misadventure" (Oxford University Press, 1999). These are rather harsh words with an irreversible tone. No wonder the child is upset! Our mistake is that we use this meaning to describe Winnie the Pooh™ when he is under the bed behind the socks to the left of the baseball mitt. In practice, unless a thing has the ability to dissolve into air or water (steam, bubbles, gases, coffee, Alka Seltzer™), the accurate information is that *it is somewhere and it will probably be found*. Farther down in the definition of *lose* in the dictionary is another meaning that is more practical for our purposes: "3) ...become unable to find; fail to keep in sight or mentally follow..." or "4) ...let or have pass from one's control or reach" (Oxford University Press, 1999). It's not that we have *ceased* to have or own this item, it's that we have *no current knowledge* as to its whereabouts. Our ability to recall, prioritize, mentally sequence, and problem solve holds all of the keys that will ultimately change the status of the item from "lost" to found. We try to remember where we saw it last or *who may know* where the item is, prioritize the likelihood of where it may be and sequence those locations into a search plan. *Winnie the Pooh™ is not lost*; he is unable to move on his own and stuck in his current location until *people figure things out*.



This is good news for a child who, without knowledge of cognitive processes, may be likely to interpret *loss exclusively and literally* as "...cease to have." When a child reports a lost item, we can emphasize that it is *somewhere, still belonging to the child*, and share the strategies that may *revert its status* to found. We can model what *lose* means in practice. Saying, "The keys are lost," may likely elicit a child's anxiety and impede problem solving. Instead, we can say, "I have lost *track* of the keys..." or "I have to *find* the keys...". By *thinking out loud* we can identify our steps toward a solution, calmly involving the child. "Let's see, Dad may know. He moved my car out of the garage yesterday. Let's go ask Dad about my keys, okay?"

Sometimes, our vocabulary related to loss can be clarified with the addition of a few key words. For example, day-to-day losses include competitive sports and academic tasks, where the meaning of *lose* is to: "5) ...be defeated in (a game, race, lawsuit, battle, etc.)" (Oxford University Press, 1999). This is a "cut and dried" face-value description of loss that a child with ASD may readily ascribe to, as in, "I lost the game...". Literally interpreted, the game is an isolated and thus *exponentially important* defeat. Other children benefit from the consideration of past and future events alongside the current activity, leading them to ultimately (if not immediately!) conclude, "I lost *this game, this time*." *This game and this time* represent



important concepts: the temporary status of the situation *and its continual and inherent connection* to other games and opportunities, both past and present. The same thing is true of a disappointing outcome on a school assignment or test. The consistent addition of a few words, like "...this time" can gradually work to "ground" the profile of the current situation, with an emphasis on its relationship to other opportunities.

Vocabulary and Death and Dying The vocabulary that parents and professionals choose is rarely more critical than in a situation where a loved one has died. The challenge is that emotions are more intense, demands on time are increased, and those directly involved are understandably tired. By remembering a few suggestions regarding vocabulary – though it may take some additional concentration or investment of time initially – a parent can save time and stress in the long run. These suggestions are: 1) increase awareness of the risks and enduring implications of literally interpreted words, phrases, or statements used to refer to those who are terminally ill or deceased, or the events surrounding a death, 2) pre-think explanations with *exceptional* care and encourage others to follow suit with the use of the same vocabulary and phrases, and 3) equipped with these considerations follow your own good judgment and faith to make a final decision regarding how, and what, to share with the child in light of your current situation.

The selection of vocabulary related to death and the events that surround it has been briefly mentioned throughout this article, but it is worth emphasizing here. First, vocabulary related to death and dying can be established early in a child's life and developed as a continuing process, i.e. in references to the dead bean plant that no longer can drink, eat, breathe, or grow; the dead fish, mouse, and hamster that can no longer drink, eat, breathe, move, or grow; and Grandpa, who has died and no longer drinks, eats, breathes, sleeps, moves, or grows. The verb *feels* also becomes important as curiosity/concern/questions related to the closing of the casket or placement of the casket in the ground arise. Ensure that the child understands the negated form of the verbs (*drink, eat, grow, move, and sleep*) prior to beginning these explanations. The word *very* can reinforce the distinction between having a cold (sick), having the flu (very sick), having a terminal illness (very, very, very sick) and being so very, very, very, very, very sick that the person could *no longer* drink, eat, or breathe *anymore*. That's why the body is so still in the casket, that's why it's okay to close the casket and place the person in the ground or cremate the body.

Working in haste or without preparation, a parent or even professional may mistakenly use terms like "asleep" or "away" to refer to the deceased. This vocabulary, if interpreted without the benefit of their intended meaning, may have enduring consequences (a child refusing to go to bed to "sleep;" a child bursting into tears because mom is picking up the keys to the car to go "away" to the funeral home). Diane Rawlings' (2000) study of bereavement and adults with ASD reinforces the point that vocabulary can be easily misinterpreted with potentially serious results:

In relation to information about death, I am continually reminded of a situation where for one individual, his own death appeared to him to be the easiest solution to the problems he was facing in his life at that time. The explicit duty of care toward all clients should direct services towards a close examination of what and how staff communicate to clients. Statements such as, 'It is sad that X died, still never mind, he has gone to a better place,' may be taken literally and lead to unfortunate consequences (p. 26).



Family and friends can benefit from having a little information, too. Despite efforts to prepare a child in advance, he or she may react in unexpected ways during a visitation or funeral. Without background information, others may be offended, make erroneous judgments, or avoid interacting with a child for fear of saying or doing something "wrong." Assigning someone in the family with the role of briefly sharing this information, or distributing a slip of paper to key individuals that briefly lists a child's current understanding of the death, his or her most frequently asked questions and suggested answers, as well as suggested vocabulary, can relieve some of the stress for the child with ASD, members of the immediate family, and those attending a funeral.

The final decision regarding vocabulary and explanation lies with a child's parents or caregiver. As a poignant case in point, I am reminded of the young mother of a child with autism who approached me during a break at one of my Social Story™ workshops. She shared with me that she had terminal cancer, and that it was likely she would live only for a few more months. She wanted to know what she could do to help her daughter, Angie - now, when she died, and in the years to come. Together we worked out a plan addressing each of these stages. Enthusiastically, she developed plans for a trunk for Angie to explore as she matured. Mom knew exactly what she wanted to say. To get Mom started, we carefully selected key vocabulary and wrote a few Social Stories. Mom decided to gather her favorite photos of the family, and her times with Angie, and write a short description of each. We also made plans for "surprise packages" containing important maternal wisdom, to be opened by Angie, one each year until she reached eighteen years of age. In the process of developing "Angie's Trunk," we laughed ...and cried. I often think of this young mother's courage in facing her own mortality, and her unshakable devotion to her role as a mother *then* - and *always*. Now, she reminds me that how we frame information about death is ultimately each family's decision.

Analogies An *analogy* is that which establishes a correspondence or similarity. For many children with ASD, an analogy can serve as a bridge between a concept and comprehension. The use of analogies with children with ASD is not a new idea, as seen below:



- The statements and writings of many children and adults with ASD contain analogies - often of high personal interest - to help describe concepts and emotions. One mother writes: *After the death of his grandfather, Christopher had "good days" (described as the Titanic before it hit the iceberg) and "bad" (the Titanic after it hit the iceberg). Christopher is very interested in the Titanic, but grandpa's death was the first time he used it as an analogy for his feelings*
- Children often contribute their own analogies to a Social Story to help them remember the information that it contains. After reviewing a Social Story describing what people mean when they say, "I changed my mind," seven-year-old Scott developed his own sentence, which was added to the Story: *When someone says, 'I changed my mind,' I can think of an idea becoming better... like a caterpillar changing into a butterfly.*
- Dr. Tony Attwood has used analogies extensively in his social understanding groups for children with Asperger's Syndrome to help them understand fairness (the Scales of Justice) and to develop strategies to manage their feelings (The Emotional Toolbox, Attwood, 2002). In addition, children in his groups have used road signs to represent the social concepts and skills they have learned.
- An analogy was used to help children with ASD benefit from Dr. Kenneth Rubin's research identifying the four steps typical children follow to enter an existing play activity (as described in *The Friendship Factor*, 2002). Drawing from Dr. Attwood's use of road signs with his social understanding groups, road signs were used to translate the four steps of group entry into a Social Story titled, *Watch, Listen, Move Closer, Ease In* (Gray, 2002, based on the work of Rubin, 2002).
- Comic Strip Conversations (Gray, 1994; 1998a), use colors as an analogy to help students identify the motivation, feelings, and intended meanings of others. Each child creates his or her own chart of colors and associated meanings.

Taking a variety of forms, and serving an even wider variety of functions, in creative hands analogies can add interest and fun to our efforts to introduce concepts that otherwise may be beyond a child's reach.

Some children with ASD may not yet be ready to understand and apply analogies. Because an analogy requires a child to understand representation and consider two lines of information simultaneously, analogies may be beyond their current grasp. That being said, they are a wonderful tool to keep "on the strategies shelf." As a child grows, so, too, will his or her ability to benefit from instructional ideas, like analogies, that may not have worked in the past.

Analogies and Day-to-Day Losses If they are carefully explained, analogies can help children understand that loss is a temporary setback and an opportunity for learning. Educationally, the best analogies are those that are highly interesting with the potential for several "connections" to different concepts within a given topic. Dr. Jerry Mulder, a



social worker for Jenison Public Schools, uses golf to teach the importance of attempting difficult tasks, the benefits of practice, and strategies to handle life's "sand traps." Students actually practice putting and other skills related to golf, alongside corresponding social and emotional concepts. Another example: A recently piloted curriculum to teach problem-solving skills to adolescents is based on an analogy of a "life suitcase," with experiences represented by destination decals (Gray, Wallis, & VanHouzen, 2003). Each lesson: 1) begins with an identical opening; 2) continues with a PowerPoint presentation to illustrate the lecture and guide the following discussion; and 3) builds skills one step

at a time with systematic review of previous material. Concepts reinforced continually throughout the program and applied to various situations include: 1) problems are temporary; 2) setbacks and losses are opportunities for learning; 3) the basic steps to problem-solving steps, and 4) the importance of "moving through" uncomfortable destinations. The program is described in more detail in Appendix C: Additional Ideas / *The Suitcase Curriculum: Traveling through Life*. In this way, a great analogy can serve as a theme, a meaningful backdrop for a variety of lessons.



In an environment where adults consistently model the use of analogies in their explanations, a child may even develop ideas of his/her own. Such is the case with Benjamin Hoekman, age eight (Hoekman, 2003). Upon learning that ideas to handle loss were being gathered for this article, he submitted a letter to me describing the use of a "worry cup". Children can literally "leave their worries" in a cup by the door to their home, to be discussed and resolved later or simply discarded if no longer a problem. Ben describes the use of a worry cup far more effectively than I do, which is why his original letter appears in its entirety in Appendix C: Additional Ideas / *The Worry Cup*.

Analogies and Death and Dying. As mentioned earlier, *Lost & Found* contains many analogies to help children understand concepts that may otherwise be too difficult. In creative hands, many of the analogies within the book may be translated into activities to enhance important concepts. For example, in this excerpt from the chapter, *The Ones We Lose*, the authors use an analogy of a board, nails, and a rubber band in their discussion of losing a mom or a dad:

Families are like a board with nails pounded in it and rubber bands stretched over the nails. Those rubber bands make a pattern. If you pull out one of the nails, the pattern of the rubber bands is suddenly different. It's the same when your mom or dad dies. Your parent was one of the nails of your family, and without that person, your family has a new shape. But you're one of the nails left in the board, and doing your best to help everybody learn to live with the new shape of the family is a very great thing to do" (p. 151).



Among the stress of a terminal illness or death, a creative analogy may seem out of place. The e-mails submitted to me during the development of this article, however, proved how analogies can retrieve the first smiles - for everyone - from among the confusion, frustration, and/or tears that follow a death. Nathaniel's father died as the result of an accident. The concept of death was difficult for Nathaniel to understand; he kept insisting that he needed to talk to Dad. Nathaniel's mother tried to encourage him to "...talk to Dad in your mind and prayers." "Okay," Nathaniel would respond, only to add, "Can I talk to Dad, please?" This cyclic conversation was increasingly frustrating to Nathaniel and his mother. The situation was resolved by an ingenious idea. Mom used a Social Story to describe how Nathaniel could *write a letter* to Dad (at the same time letting Nathaniel know it wouldn't be possible for Dad to write back). Nathaniel wrote a letter, clearly addressed to DAD: HEAVEN which was tied to a helium balloon and released outdoors (clear of all trees and obstacles!). Nathaniel's requests to talk to dad diminished, replaced by several subsequent letters mailed via balloons. Over time, the frequency of Nathaniel's letters decreased, but did not disappear entirely. Several years after his father's death, Nathaniel still writes to his dad to relay important events, thoughts, and feelings - including one memorable letter that described the helpful properties of helium!

In summary, we have many accommodations within our reach that can “work both ways” to improve our communication with people with ASD. In addition to enhancing meaning with the use of visual supports, when it comes to loss and learning, our most important accommodations may involve vocabulary and the use of analogies. Children with ASD frequently express and interpret information at face value; in return, we can clarify our communication by harnessing a little extra caution. This, coupled with an effort to teach the intended meanings of words, can translate a disaster of missed meaning into a learning opportunity. Though they may not be effective with some children, analogies can incorporate interesting activities and objects that recruit and hold a child’s attention. Especially when applied to situations where emotions run high - as they do surrounding the death of a loved one - an analogy will be long remembered and may help not only the child with ASD, but others working on his or her behalf. With thoughtful application, our careful choice of vocabulary and creative use of analogies can build the bridge between concept and comprehension - leading to new learning opportunities on the opposite shore.

Affirm Feelings



Often the most difficult aspect of working with a child with ASD are those times when it seems impossible to determine what exactly is causing the child such distress. What is he thinking? What is she feeling? This can leave us frustrated in our efforts as we try to understand, struggling to be *sympathetic* or *empathetic*. It may not be possible for us to feel sympathy or empathy, and that may be where part of our exasperation arises. The root words, *sympathy* and *empathy* are nouns that by definition require an accurate appreciation of another person’s point of view. Sometimes, we don’t have access to that information, placing sympathy and empathy out of our emotional reach. It’s just not possible.

Affirm, in contrast to sympathy and empathy, is always a verb. It is *acknowledgement* of the validity and importance of another person’s feelings without the requirement of knowing what that person is thinking or feeling. Affirmation says, “I know you and I are currently in very different emotional places, and that’s okay. I am on your team and we are in this together.” This is not to “give-up-the-ship,” but to support the child until a solution that is workable to all parties is discovered. In those instances where the source of distress is difficult to identify or the events leading up to it are hard to trace with any certainty, affirmation plays a large and helpful role. This section describes affirmation in action, at work among day-to-day losses and those resulting from terminal illness and death.

Children with ASD frequently do not have the fluent command of tone of voice, facial expressions, and body movements that provide us with important clues as to what someone *means* or *feels*. For example, monitoring a young boy with ASD in the classroom whose facial expression and tone of voice have remained absolutely neutral and “flat” for an extended period of time, we may not “pick up on” his increasing frustration with the current activity. Thus, we are surprised at his outburst moments later. Subsequently, we may refer to his tantrum as occurring “totally out of the blue” and “for no apparent reason.”

Increasingly, the creative use of visual materials and supports are helping children with ASD identify and express their feelings. Comic Strip Conversations, feeling thermometers (Attwood, 1998), and other emotion gauges (Prizant et.al., 2003) support the exchange of information between child and parent or professional. For example, as a child begins to feel uncomfortable, he can let his parents or teacher know by indicating what he is feeling, and the intensity of that feeling, on a representative scale. Knowing what a child is feeling, sooner, we can teach emotion regulation skills before a child’s loses control. Over time, the systematic use of visual supports lays important groundwork for their use in situations where a child’s feelings are more intense.

Affirmation and Day-to-Day Losses Each day provides a wealth of opportunities to affirm a child's emotions, positive and negative, on-the-spot and in retrospect. When it comes to the feelings that loss can elicit, active affirmation can catch a feeling before it explodes with nowhere to go - even in the course of the fast sequence of activities in a busy day at school or home, as this teacher describes:



I was out and my assistant was at lunch when the bus arrived, so my substitute met the bus. Eddie, age 3, looked at the unfamiliar lady, froze, and grabbed the bus driver's hand. Eddie's bus driver is a kind and understanding man. Sensing Eddie's confusion in response to an unfamiliar staff member, the bus driver went with Eddie to his classroom. Once in the familiarity of the classroom, Eddie relaxed and the bus driver was able to continue his duties.

A day's events can develop quickly; so, too, the feelings that follow. Advance planning can help to ensure that visual supports, like picture icons, are available when needed. The simple act of making sure they are at hand is evidence that adults recognize and affirm the challenge of having ASD. John, age 3, walked to his bus at the end of the school day. He put one foot on the bottom step, looked up, and stopped in his tracks because his usual bus driver was not there. He began yelling, "NO!", cried, and refused to board the bus. His teacher patiently took him off the bus, showed him that the number of the bus was correct, handed him a "home" icon to carry with him, and went with him as he successfully boarded the bus. Considering John's distress upon entering the bus, and that heightened emotions can interfere with a child's availability for explanation or reason, it is likely the picture icon took the direct route (though John's confusion and anxiety) to comprehension. In contrast, without the picture icon, the unassisted words of John's teacher would have likely become either entangled in his confusion or quickly placed on a detour past comprehension, adding to the already heavy traffic headed for increased distress.

Whereas some events in a day develop quickly, others arrive like an airplane landing on a crowded expressway. The sun is out, the sky is blue, and the gas tank is full. The children are happy. We're on the right road and ahead of schedule. All is well except for - what's that coming straight toward the yellow car in front of us? Flight #4892 bound for Chicago... and landing on I-94 west? Somehow, we weren't expecting that. Similarly, children with ASD encounter sudden insults to their day and expectations, assaults on their understanding of how things are supposed to go. For example, while his sister quietly read a book in the back seat, Ralph, age 3, cried, screamed and kicked as their car approached a barricade in the road and had to take an alternate route to school. Ralph's mom did the best she could to console him and share information. She returned home and wrote a Social Story titled, *The Driver Knows the Way so We're Okay*. Encountering the barricade the following day, the back seat remained calm and quiet. More importantly, as the school year ended and summer road work cropped up everywhere - along with more barricades and detours - Ralph stayed calm, but did inquire each time, "The driver knows the way so we're okay?"

In situations like Ralph's, much of our affirmation is in retrospect. Unable to predict the pitfalls, we reflect on what may have caused them and write a Social Story to share information with the hope that similar events in the future will go more smoothly. A case example of "in retrospect" Social Stories that affirm - and inform! - occurred in my own school district early this past fall. One of my early elementary students, David, was having difficulty on several fronts. A question as to whether his placement in a general education classroom was advisable for this year was posed to me by his parents, principal, and teacher. David had several emotional outbursts in the first few weeks of school, many resulting from day-to-day losses. He frequently made literal interpretations of the comments and directives (Social Losses / missed meanings); found mistakes on spelling tests intolerable (Performance Losses), and had difficulty leaving assigned tasks to complete at a later time (Loss of Routine). Faced with the frustration that these situations caused, David often responded to the supportive efforts of the principal, teachers, and his instructional assistant in a disrespectful or insulting tone of voice (Loss of Control).

A Social Story topic was identified, developed, and implemented for each of these issues. As a team we have continued to identify topics and Stories throughout the year. Several other Social Stories for David have praised skills

that he has mastered and activities he does well, and applauded his friendly gestures to others. At this writing, David's "placement prognosis" is excellent and he is completing a very successful year. We are all very proud of his genuine accomplishments – academically, on the social front, and especially in his ability to turn loss into learning. (Many of David's Stories are in Appendix B: Social Stories & Loss / *David's Stories*)



Affirmation and Death There are few better uses for affirmation than as we approach the task of sharing the news of the death of a loved one with child with ASD and support him/her in the days that follow. There is the possibility that we may never know for sure how the child feels, ruling out any chance we may have to be empathetic or sympathetic to his or her experience. For all children with ASD, the new and unfamiliar activities and the feelings of others are likely to be difficult to appreciate. Among the many unique profiles described earlier that we may observe among children with ASD in response to a death, we can count on three practical implications: 1) each will present a unique mixture

of many individual factors; 2) confusion is likely to play a central role as a child observes and responds to the situation as it unfolds, and 3) *tangible affirmation* may be our best and most effective response option. Each is explored in this section.

Each child with ASD is unique. This, coupled with the relative infrequency of the events and emotions that surround the death of a loved one, makes it especially difficult for adults to accurately anticipate a child's response. How are we to know what a child may say or do, or what that child may need, if this is his first exposure to the death of a person? The dad who rehearses and re-rehearses how to share the news that mom has died, can prepare himself for only half of what may ultimately occur. Anything can happen, and this adds uncertainty to his already stressful situation. His son may be severely distressed or disarmingly practical with questions about who will make dinner, pack lunches, and wash the clothes. The genuine art lies in respecting the differences that may become apparent after his son hears that "Mom died...". Regarding his reaction without interfering judgments, in light of individual abilities and challenges, dad is free to take his next step: to provide the support and/or the information that his son needs.

Children with ASD are likely to be confused by the death of a loved one. The information a child currently understands about death will be reflected in his or her behaviors, statements, and if we're lucky, direct questions. We can use our understanding of how typical children view death at different ages as a frame of reference as we watch, and listen, for clues as to our next step with *this* child. In addition, children's literature may be helpful, and there are many that address specific situations, for example, the loss of a family pet, mother, father, or sibling. Also, many funeral homes have children's libraries, so that bereaved families can benefit from these resources without having to purchase them (see Appendix A: Resources for Adults & Children / *Resources for Children*).

Finally, we can *meaningfully affirm* a child's experience by responding with *tangible vehicles* for the identification and expression of their feelings related to the death of a loved one. Similar to the mom who used a helium-filled balloon to enable her son to communicate with his deceased father, here are other ideas:

- *Continuing use of strategies already in place:* emotion thermometers, Comic Strip Conversations, etc., that without a concerted effort may slip from routine use.
- *Children's literature* and activity books (See Appendix A: Related Resources for Adults & Children / *Resources for Children*).
- *This Will Stay the Same* list: A child's list of daily, weekly, monthly, and yearly events that have occurred prior to the death, that will occur once again. A child can discover new items to add to this list as time progresses.
- *A Calendar:* Though it may seem out of context in light of the emotions of others, a calendar identifying when routine events are to re-start, and a corresponding Social Story that emphasizes the data surrounding the return to the familiar (identifying dates and times that Dad returns to work or dance classes for Susie resume) can be reassuring for a child whose sense of social predictability and order is based on those

events. Similarly, a "paper chain" (with a representative photo at the top) for a younger child to count down the days until returning to his home town and preschool, can help a child realize time *is* passing and he will be resuming his usual routines very soon.

In summary, affirmation is empathy and sympathy without the benefit of accurate guesses regarding another person's experience. Affirmation starts from social scratch, taking its cues from a child's responses and respecting the unique elements within them. In terms of day-to-day losses, affirmation ensures that supports that clarify communication are in place and always readily available, or works in retrospect to pave future roads with "concrete" and accurate information. Understandably, in terms of death and dying, confusion may be one feeling shared by many children with ASD as they learn of the death of a loved one, try to make sense of the sudden changes or variety of feelings that surround them, and attempt to figure out what is expected of them. Recruiting information from experts in grief in childhood, and providing tangible resources to help children identify, add detail to, and express their feelings and memories, can help us as parents and professionals structure our own supportive role with a child with ASD following the death of a friend or family member.



Associations

As mentioned earlier, a child with ASD is likely to need assistance to make "connections" between past and present experiences, to retrieve information relevant to his/her current experience. Relevant information in this case includes recall of 1) how a similar problem was solved in the past (*Last time I lost a block it was under the bed...*), or 2) that reassuring inner-voice of emotional self-support that can carry a child through an uncomfortable current experience (i.e. *I don't like being in this dentist chair, but, I do get that toy at the end... and this will end soon*). Whereas children with ASD often associate loss with negative emotion, or may mistakenly make a connection between two simultaneous but unrelated cues, our goal is to encourage them to identify the accurate links of their past, present, and future experiences; to use strategies that gradually, step-by-step, lead to cumulative learning and positive feelings of accomplishment.

Associations and Day-to-Day Losses The list of ten categories of day-to-day losses on page 3 of this article is incomplete; there are a host of others. Within each category, a child will have experiences that in one way or another hold a similarity to a past encounter, or a lesson that can be applied in the future. Just as we have learned strategies to enhance the meaning of information we share in the present tense, we can demonstrate the cumulative links among human experience in the same way. It may, in fact, require only a *simple expansion*

of our current visual supports. Considering the wealth of categories of losses we can work from, the possibilities for creating links - in a meaningful way - vastly exceed the reach of this article. For that reason, in this section we will use two examples, the first from the category of *Lost Stuff*, the second from *Loss of Routine*, as a focus for our discussion.

Lost items can be documented, and their relationship to one another demonstrated, in a *Solutions Notebook*. Children with ASD often have focused interests, and their free time tools revolve around fewer activities than their

typical peers. Chances are we can readily identify the items a child is likely to lose. This makes it easier to develop a plan to demonstrate the lessons within those losses. The first page of a Solutions Notebook has a picture schedule that identifies the basic steps to find a lost item, and an accompanying Social Story (described in detail in Appendix B: Social Stories & Loss / *Writing Social Stories about Loss*). On the following page is a *Finding Form*, that structures the search for a specific item. It includes questions about where the item was last seen, who was with the child, who may have information, etc. Subsequent pages of the Solutions Notebook record where lost items have been recovered in the past, one item per page. For example, Sam frequently loses blocks, so he has a page for blocks. A picture of a block is at the top of the page. Whenever a block is misplaced, and then found, its location is recorded. The next time a block is lost, Sam follows the list, looking in those locations where blocks have been found in the past. Meanwhile, his father launches a search of the immediate area. The cumulative result is a reference of the steps to follow to recover lost things, and a notebook to replace a child's distress with the recording of valuable discoveries.

We may not always need to create a notebook or develop something new to help a child tie related experiences together; the resource we need may already be on the shelf in photo albums. Each year the holidays arrive with an array of events and activities that – while they may be repeated in form and sequence – occur far more infrequently than, let's say, brushing our teeth. While typical children recall the events of last Christmas or Hanukkah, the child with ASD may be distracted by the many changes to the daily routine and the anxiety that causes. A review of last year's photographs, perhaps incorporated as illustrations for a Social Story that describes the similarities to the family's plans this year, may be very helpful. Some things will change, of course. John may not get pajamas this year, we may make sugar cookies in place of gingerbread men. We'll get back to school and our typical routine this year on January 5, last year it was January 3. By noting in writing the similarities, differences, and expectations within each activity, a child has the benefit of advance notice coupled with important references to his or her past experiences. Listening carefully, we may also discover some accommodations that may make this year's holidays easier than those in the past.

The more similar experiences are documented and organized for future reference, the greater the amount of recorded and indisputable evidence that lost items are often found, other people have helpful ideas, problems are temporary, and resolutions of problems hold valuable lessons: small, cumulative lessons to prepare our children to handle life's larger losses.

Associations and Death and Dying Making associations between what is learned about the life cycle from bean plants and hamsters may seem a long and vicarious leap from the death of a loved one. Still, they hold some important similarities, and for a child with ASD, a valuable reference to frame his or her current experience with death. The genuine art lies in helping children understand the common ties among all living, dying, and deceased plants, animals, and humans; as well as showing a child with ASD how recalling events and sharing feelings helps people move through grief – to ultimately remember their own personal collection of past people.

Similar in concept to the Solutions Notebook, a *Life Scrapbook* can document a child's experiences with both life and death, laying the groundwork for the day when a loved one dies. Opening with a simple Social Story describing the life cycle, the following pages are a child's personal record of that same information. A page is entered for each life placed in a child's care or home, with notes recording the important dates and events of each. Beginning with the package of bean seeds on the first page, and followed by pet photos, drawings and observations on subsequent pages, a *Life Scrapbook* is a child's personal, cumulative documentation that life takes many forms with a variety of beginnings and endings. This book may be referred to in the process of sharing with a child that a loved one has died, whose life may subsequently be recorded on the next page entered into the Life Scrapbook.

When a loved one dies, inevitably people recall – and are comforted by – experiences they have had with the deceased in the past. Recalling the last time they talked or worked together, gradually helps them to accept that it *is and always will be* the last time; the person is no longer alive. While gaining acceptance of a death, memories gain a

heightened status, as the keepers of what is now even more valuable than it was yesterday, when the person was alive. Memories, unlike the person who has died, can be visited again and again, any time.

Memory is also a cognitive theory that can be represented for the child with ASD with visual strategies and tangible - perhaps ongoing - activities, for example:

- **I Remember Poster:** A simple stick figure face and very large thought symbol is drawn on a piece of poster board, and mounted in an accessible location. As a child recalls things the deceased said or did, they are recorded in the thought symbol. There may be a photo that can illustrate his or her thoughts. To make it easier to "keep up", a pencil can be attached to welcome a child to make additions on his own if he/she is able. The poster may be displayed at the funeral home, providing a tangible source of AOK topics for the child's conversations there, with additions to the poster encouraged long past the funeral.
- **Memory Boxes:** A Memory Box is a personal collection of photos and/or drawings of the deceased, notes that preserve past experiences, and video tapes, etc. A child can be assigned responsibility for a *collective* memory box, where the thoughts and feelings of others are also included.
- **Memory Boxes without a Box:** These activities include memorial websites, the development of a memorial newspaper, a collection of poetry or a journal devoted to topics and feelings related to the death; or a "memory table" for a limited time at the funeral home (which may provide photos and accomplishments of the deceased to structure a child's conversation).

In summary, adults can play a critical role in helping children with ASD tie similar experiences together, part of an ongoing effort to help them regard setbacks as temporary destinations with opportunities for learning en route. Day-to-day losses often arrive unexpectedly; documenting their resolution provides reassuring data that setbacks are temporary and matched by an equal number - *or almost an equal number!* - of solutions. Childhood experiences with the lives of plants and pets hold within them an important curriculum of life and death, that prepares them for the loss of loved ones later down the road. The art lies in continually harnessing this valuable curriculum to benefit children with ASD. Otherwise, due to its temporary nature, it will pass us by each and every time.

Summary

Loss arrives as an uninvited destination in life - and presents an opportunity to translate experience into wisdom. To those who can eventually see through its disguise as a misplaced item, forfeited opportunity, or passing of a friend or loved one, loss leads to new beginnings, creative ideas, and the discovery of emotional strength. As we grow, each setback ultimately prepares us to work through the next - an incredible system that applies relevant past experience to current tasks and future applications. On their own, children with ASD find this task to be incomprehensible. With the creative support of parents and professionals, children with ASD can also learn to organize their own unexpected destinations to discover the personalized lessons that they hold.



Five "destinations" in this article identify its main sub-topics:

1. **Childhood Losses & Learning:** Loss is an important learning opportunity, a unique curriculum based on personal experience.
2. **Children and Death:** The profile of grief changes as a child grows, and serves as a frame of reference for understanding loss and children with ASD.
3. **Loss and Children with ASD:** Children with ASD may respond to loss in a way that is very similar to their peers, but often their responses are more intense, unique or opposite in comparison.
4. **Appreciating the Differences:** Challenging responses to loss may be due to differences in a child's perception of events and information.
5. **Guiding Children with ASD through Loss:** Introduces new guidelines to help children with ASD learn from all losses.

Through their own struggle to effectively perceive and respond to the events and interactions that surround them, children with ASD always end up teaching us to be better people than we were the day before. It's interesting that regardless of the specific topic, every article that improves our understanding of children with ASD ultimately improves our understanding of all people. It is not surprising, then, that in the search for effective strategies to bridge the gap between typical people and those with ASD we uncover philosophies and attitudes that are applicable to all human experience. If "social understanding" is a shared destination for people with ASD and those who work on their behalf, it is this author's sincere hope that through this article we have traveled a little closer toward that goal.

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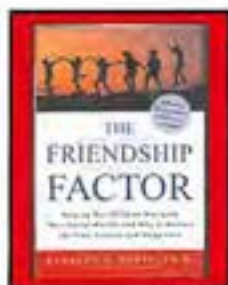
Gray's Guide to Loss, Learning, and Children with ASD

Appendixes A, B, & C contain resources and additional information mentioned in the article, *Gray's Guide to Loss, Learning, and Children with ASD*.

APPENDIX A: Resources for Adults and Children

Appendix A reviews and lists some resources about loss in childhood that have the greatest potential for practical application on behalf of children with ASD.

Resources for Adults



Bookstore and library shelves contain many more books about bereavement in childhood than the day-to-day setbacks children encounter. Consequently, one book, *The Friendship Factor*, by Dr. Kenneth H. Rubin (2002) is a rare find. It explores friendship in childhood, addressing the social setbacks that typical children encounter as they grow. Summarizing over twenty years of study of the social connections of childhood, the book explores the specific concepts and skills that largely determine social and emotional success, or exclusion from peers. Released in paperback on May 1, 2003, the book describes the social errors that children make, and *what to do to help them succeed*. Dr. Rubin's book contains important advice for anyone who works on behalf of children, including children with ASD. (Dr. Rubin is sharing a workshop day with Carol Gray at *Making Social Connections*, the third annual conference of The Gray Center for Social Learning and Understanding on October 14, 2003. See page 43 of this issue for more information.)

There are many books to help parents and professionals guide children through the death of a parent, sibling, relative, or friend. Though they do not directly address the unique twists and turns that we encounter with children with ASD, they contain many ideas that are very applicable. The following books meet the criteria as sensitive, practical, and reader-friendly with plenty of usable information:

- *35 Ways to Help a Grieving Child* (The Dougy Center, 1999). This book is a wonderful guide that shares ideas to support a grieving child, with much of the advice applicable to children with special needs. In reference to the desire to protect children from the harsh realities surrounding a death, the author explains "...whether we tell them directly or not, children usually learn the facts in one way or another, either by overhearing adults or other kids talking, or in some cases, from television or newspapers. It only complicates a child's grief when someone close to her lies about the cause of death and the deceased..." (p. 5)
- *Helping Children Cope with the Loss of a Loved One* (Kroen, 1996) is another great resource for parents and professionals to have ready on the home bookshelf. The idea of using multiple "verbs", mentioned in the article (p. 5), comes from this text, along with ideas for using art to help children work through feelings, strategies for moving on after a funeral, and reminders to parents to also take care of themselves. This helpful guide translates background information into "what to do" recommendations.



*The Friendship Factor is now available in paperback from The Gray Center for Social Learning and Understanding www.TheGrayCenter.org

- *Your Grieving Child: Answers to Questions on Death and Dying* (Dodds, 2001). Some children with ASD are highly inquisitive, and the death of a loved one may trigger a series of disarming questions. Providing a good answer for a child can be a challenge. This book comes to the rescue with answers to questions like, "Is she a ghost now?" (p. 17) or "Am I bad because I kind of feel glad he's dead?" (p. 38)
- *Helping Teens Cope with Death* (The Dougy Center, 1999). There are few books that focus on death and adolescence, and this one is packed full of information, first-hand insights, and practical guides for parents and professionals.

Resources for Children

Children's literature is becoming a great resource for books about loss. Though there are many more children's books about death and dying than day-to-day losses, the number of books addressing life's smaller setbacks are gradually appearing on the shelves. Plus, we can look to children's literature for interesting, real-life role models: historical figures who encountered great setbacks and losses, only to emerge to make significant contributions.

To help children ages 8 - 12 work through day-to-day losses and those that result from lost friendships, moving away, divorce, death or dying, there's *Lost and Found*. For younger children, a recently released book, *Who Took My Shoe* (Emigh, 2003), guides young children with ASD through the steps of recovering lost things. Brett has lost his shoe, and along with his dog, Herman, launches an investigation to find it. He explores the possibilities: *who* may have his shoe, *what* may have happened to it, *where* may he have left it, *when* he could have lost it, *why* it happened, and *how* to find it:

Should I dig for it in the back yard? No.
Should I do a "find your shoe dance"? No.
Should I call the police?
No. It's not an emergency.
Then, how will I find my shoe? (p. 12)

The shoe is recovered, and Herman holds many important clues. The repetition throughout the story, predictable format, simple text, along with bright, colorful illustrations and humor, make this a book with plenty of instructional potential.



There are other children's books that reinforce the concept that a loss is a temporary setback that can lead to new discoveries. These include:

- Autobiographies of Thomas Alva Edison (Adler, 1996; Cousins, 1965).
- Autobiography of W. A. Bentley, *Snowflake Bentley* by (Briggs-Martin, 1998), and their photographic collection of snowflakes, *Snow Crystals*, by W. A. Bentley and J. W. Humphreys (1931).
- Life stories of other people who made significant discoveries as the result of serious personal setbacks, for example, Helen Keller and Louis Braille; or leaders in a child's interest area who have learned and succeeded in response to loss.

Children's books can share concepts related to the life cycle, *before* the death of a loved one, as well as helping children understand death and dying. For example, *Lifetimes* (Mellonie & Ingpen, 1983) explains life cycles through a simple and straight-forward discussion of how life begins, ends, and what happens in between, using a wide range of examples from plants, to ants, to people. *When a Pet Dies* (Rogers, 1988) picks up where *Lifetimes* leaves off, exploring the experience of owning a pet and the variety of feelings that a young child may have when he or she dies.

There are many books to support children when a mom, dad, or sibling is terminally ill or has died. *What on Earth Do You Do When Someone Dies?* (Romain, 1999) is a straight-forward book for children that patiently answers basic questions about death, describes several possible feelings related to the loss of a loved one, and reassuringly coaches a child regarding what to say and do one step at a time:

Some families hold a ceremony called a funeral. This type of service often takes place in a house of worship or a building called a funeral home. ...At these services, family and friends talk about the loved one, sing, pray, or play music. This is how they mourn the loss of the loved one or express their grief. ...Funerals, memorial services, and other ceremonies like this are important. But your parents may not want you to go. They may think you'll be too sad or frightened (pp. 48-49).

In addition, *Help Me Say Goodbye* (Silverman, 1999), is a great "match" for a child who loves to draw. Each page contains brief text and plenty of room for a child and/or parent to write or draw. For example, "If you could bring something to the funeral for you and your special person, what would it be? Draw or write your suggestions" (p. 10). A word of caution to adults: beware of literal interpretations. Some text may be misleading to a child with ASD, or lead to unwarranted or premature fears.

The children's books listed below and on the following page were selected for their practical value for children with ASD. Reviewing each with consideration of a child's ability, and the possibility of literal interpretations, will help you select the best books for the child in your care. Ages are approximate; modifications in vocabulary, format, or presentation may be required to help a child relate the text to his or her personal experience. The titles are organized into three main color-coded categories: *Activity Books*, *Story Books*, and *Chapter Books*.



Activity Books

Biale, Rachel & _____ (children using the book) (1997). *My Pet Died* (4-8 years)
32 pages with plenty of blank spaces for writing, artwork.
Tricycle Press, P.O. Box 7123, Berkeley, California 94707
ISBN 1-883672-51-1

Silverman, Janis (1999). *Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies* (6-9 years)
32 black and white activity pages for children to complete.
Fairview Press, 2450 Riverside Avenue, Minneapolis, Minnesota 55454
ISBN 1-57749-085-1 Website: www.fairviewpress.org

Eldon, Amy (2002). *Angel Catcher for Kids: A Journal to Help You Remember the Person You Love Who Died* (9-14 years)
62 color journal-completion pages. For more information about the work of Kathy and Amy Eldon: www.creativevisions.org
Published in China. Distributed in the United States by Chronicle Books LLC, 85 Second Street, San Francisco, CA 94105 Website: www.chroniclebooks.com; distributed in Canada by Raincoast Books, 9050 Shaughnessy Street, Vancouver, B.C. V6P 6E5
ISBN 0-8118-3443-3

Story Books

Rogers, Fred (1988). *When a Pet Dies* (3-7 years)
27 pages with simple text and photographs.
The Putnam & Grosset Group, 200 Madison Avenue, New York, New York 10016
ISBN 0-698-11666-6



Mellonie, Bryan & Ingpen, Robert (1983). *Lifetimes: A beautiful way to explain death to children* (4-7 years)

37 pages with simple text and color illustrations.

A Bantam Book published by Kyodo Printing Co (S'pore) Pte Ltd

ISBN 0-553-34402-1

Harris, Robie H. (2001). *Goodbye Mousie* (4-7 years)

24 pages with color illustrations.

Published by Margaret K McElderry Books, an imprint of Simon & Schuster Children's Publishing Division, Avenue of the Americas, New York, NY 10020

ISBN 0-689-83217-6

Stickney, Doris (1970). *Water Bugs & Dragonflies* (5-9 years)

26 pages with color illustrations.

Published by United Church Press in 1970. Subsequently published by The Pilgrim Press, in Cleveland, Ohio, in 1982 & 1997.

ISBN 0-8298-1180-X

White Pellegrino, Marjorie (1999). *I Don't Have an Uncle Phil Anymore* (4-10 years)

27 pages with pastel illustrations.

Published by Magination Press, American Psychological Association, 750 First Street NE, Washington, DC 20002 Web site: www.maginationpress.com

ISBN 1-55798-559-8

Viorst, Judith (1971). *The Tenth Good Thing about Barney*

25 pages with black and white sketched illustrations.

Published by Aladdin Paperbacks, Simon & Schuster, Children's Publishing Division, 1230 Avenue of the Americas, New York, New York 10020.

ISBN 0-689-71203-0

Brown, Laurie Krasny & Brown, Marc (1996). *When Dinosaurs Die: A Guide to Understanding Death* (6-10 years)

32 pages with color illustrations.

Published by Little, Brown and Company

ISBN 0-316-11955-5

Chapter Books

Gellman, Marc & Hartman, Thomas (1999). *Lost & Found* (8-12 years)

Published by Morrow Junior Books, a division of William Morrow and Company, Inc., 1350 Avenue of the Americas, New York, NY 10019 web page: www.williammorrow.com

ISBN 0-688-15752-1

Kids Write Through It (8-12 years). A collection of essays by children. 124 pages.

Published by Fairview Press, 2450 Riverside Avenue South, Minneapolis, MN 55454

ISBN 1-57749-081-9

Romain, Trevor (1999). *What on Earth Do You Do When Someone Dies?* (8-12 years)

Pocket-size 72 page book with black and white sketched illustrations.

Published by Free Spirit Publishing, Inc., 217 Fifth Avenue North - Suite 2000, Minneapolis, MN 55401-1299 help4kids@freespirit.com **ISBN 1-57542-044-4**



Appendix B: Social Stories & Loss

Writing Social Stories about Loss

Writing a Social Story about loss can be difficult due to the wide variety of possible topics and the abstract concepts within each and every one! The following background information and writing hints can simplify the process and improve the final product.

Social Stories can provide advance notice regarding day-to-day losses on several fronts. Using the list of categories of day-to-day losses on page 3 of this article, what follows are examples of general topics (stated as Story titles) to get you started:

1. Lost Stuff: *My Team for Finding Things, Steps to Remembering "Where It Is," Our Finding Plan.*
2. Performance & Competitive Losses: *What it Means if I Win / Lose, What Children Learn when They Lose.*
3. Loss of Control: *Unexpected Noises; Steps to Staying Calm; What Just Happened? Adults who Know.*
4. Loss via Sharing: *One Candy Bar and Two Children, What Sharing Time Really Means.*
5. Loss of Information: *How to Use My Planner, Why People Write Things Down, Steps to Finding Information.*
6. Lost Opportunity: *Not Today but Someday, What "Rained Out" Really Means.*
7. Loss of Routine: *Many Great Ways to Finish My Work, Substitute (Supply) Teachers Know What to Do, Why Children Act Different with a Substitute (Supply) Teacher.*
8. Loss of Health or Ability: *What I Still Can Do, In Seven Days I'll be Healthy, My Getting Back in Action Plan.*
9. Social Losses: *What Divorce Means, As Children Grow their Friends May Change, How to "Talk" to Ben after he Moves to Kansas.*
10. Emotional Losses: *My Steps to Feeling Better, How to Use My Feeling Thermometer, Steps to Keep My Patience Longer.*

Social Stories™ also have a special role in explaining death and dying to a child with ASD. Long before anyone dies, Social Stories can relate a child's personal experiences to the life cycle, and answer a child's questions about death. Or, when someone has died, a Social Story can help parents find the right words, and describe the details and expectations of events surrounding a funeral and burial. Concepts that may be addressed include:

- Characteristics that living things and/or beings share (the ability to drink, eat, move, breathe, and sleep);
- Dead plants, animals, and people cannot/do not drink, eat, breathe, move, or sleep;
- Sometimes, pets and people die after becoming very, very, very, very, very, very, sick or old;
- Some routines temporarily change when someone is very, very, very ill or there is an accident or emergency, or when someone dies;
- Many things stay the same when there is an illness, emergency, or death (love, having a home, having meals and a place to sleep, taking baths, being cared for, etc.);
- Description of a child's role and how he or she can help;
- Funeral Rules (there are some!);
- Good topics for children at a funeral home, funeral, or wake;
- Beliefs related to a child's faith or religion;
- Beliefs related to another person's faith or religion;
- Doctors and nurses help people stay healthy and care for those who are sick or injured (not necessarily making people completely well again);
- Sometimes *healthy* people go to hospitals to visit others, or for check-ups or tests; and
- Mom and Dad are very, very, very young and most of the time they are healthy. They can easily drink, eat, breathe, move, and sleep and will probably be able to for many years.

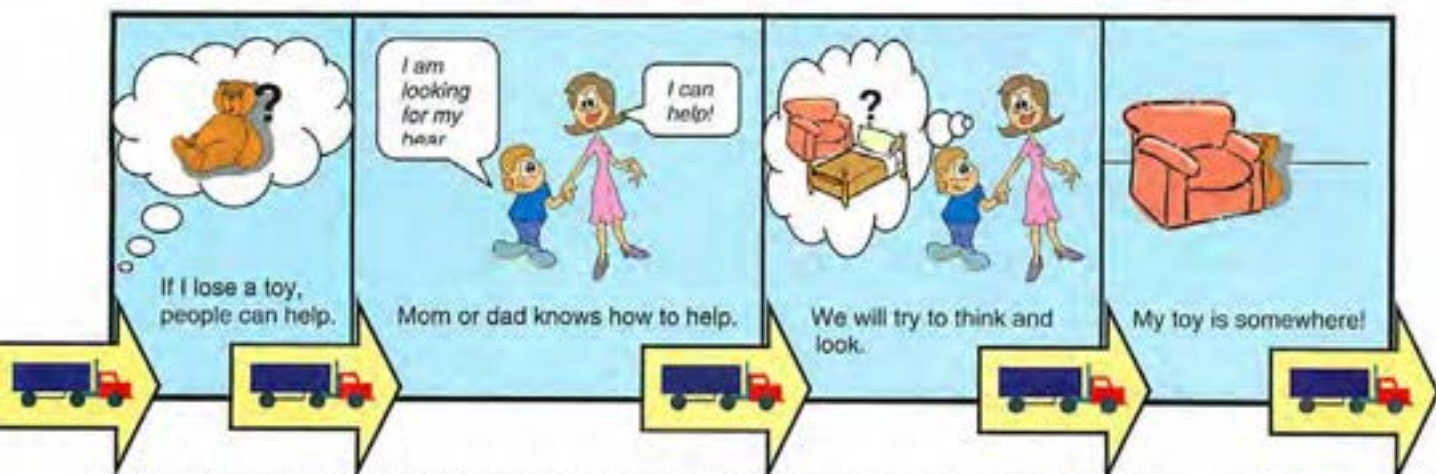
Harnessing learning opportunities and sharing important information with Social Stories can pave the road for a child with ASD, minimizing the surprise element involved in navigating through each day or the death of a loved one.

As Social Stories tackle loss, *Split Section Social Stories* may frequently be helpful. A *Split Section Social Story* (described in detail in *The Advanced Social Story Workbook*, Gray, 1998b) uses a modified format to address issues surrounding *simultaneous topics*: two or more events, activities, or responses that occur at the same time. For example, a child has difficulty understanding that he can choose only one of three possible activities this Saturday afternoon: a movie, a visit to the zoo, or the beach. For a child who cannot conceptualize that others "do still exist" when they are out of view, a *Split Section Social Story* can help. Some pages are cut horizontally to describe and demonstrate individual experiences that occur at the same time. Solid pages describe when everyone will be together:

- Mom and I will eat breakfast together (solid page). Then, Mom goes to work while I am at preschool (page split in half). At dinner we will eat together at home (solid page).
- On Tuesday we all fly to Boston (solid page). After we land, Mom will go to the funeral home, Dad will run three errands, and I will stay with Aunt Margaret (page split into three equal sections). We eat dinner at Aunt Margaret's tonight (solid page).
- Dad tucks me into bed each night (solid page). On most nights when I sleep, Dad stays home. He usually reads a book or watches television until about 11:00 (page split in half). In the morning, we have breakfast at the kitchen table (solid page).

For children who are more advanced, a split section Social Story can also describe varied responses to a single event. For example, Uncle Henry died (described on the opening solid page). Dad is Henry's brother. Dad has known Henry all his life. Dad feels very, very, very, very sad; Mom has known Henry 20 years, and she is very, very, very, very sad; I never met Henry because he lives in Germany, so that may be why I feel okay (page split three ways). In a while, everyone in my family will feel okay again (solid page).

The format of a Social Story can also help to illustrate two important concepts related to loss: 1) people move through losses, and 2) the discomfort of a loss is temporary. To do that, the Story is illustrated with a picture schedule "with a twist": the addition of icons that represent movement through the sequence. For example, a picture schedule is developed to illustrate four steps to follow when something is lost; each step represented by one square. A symbol or icon is placed on the vertical lines that separate the steps to indicate moving from one to the next. It may be something as simple as an arrow, or as interesting as a truck, or both! A corresponding Social Story provides additional information, describing each of the steps on the schedule. The icon used in the picture schedule is also placed in the lower right hand corner of each page of the Story, indicating to the child to keep moving - *turn the page* - to the next step. The Story makes frequent reference to "...traveling or (moving on to) the next step." This reinforces the importance of not getting stuck and the promise of more comfortable destinations in the near future:



"The childhood perception that people who leave from view have "disappeared forever" has been described by Gunilla Gerland, an adult with autism, in her book, *A Real Person: Life on the Outside* (1996, translation into English, 1997).

In addition to modifying the format of a Social Story, some topics may benefit from the use of fictional characters. Fictional characters are not new to Social Stories. The Story, *Watch, Listen, Move Closer, Ease In* (Gray, 2002), used a fictional character, David, to describe the four steps that children follow to enter an existing play activity. In the Social Workbook, *Gray's Guide to Compliments* (Gray, 1999), fictional characters were used extensively to demonstrate the concepts and skills that surround an effective compliment. Fictional characters can "go first" to demonstrate how social concepts or skills can be used. In terms of the topics related to loss, a fictional character can serve as a guide to a new situation, for example, visiting a funeral home. In situations where feelings are difficult to identify and express, a fictional character can explore the possibilities. However, if a child is not yet able to relate the experience of a fictional character to his or her own situation, the meaning may be lost.

Rarely is vocabulary more critical than in Stories that are about loss. The words we select can make the difference between clarity and confusion. Considering the feelings that loss-related topics can elicit in children with ASD, misleading vocabulary may be all it takes to derail our best effort to share information. Even with caution regarding literal interpretations, a child may get caught in subtle variations in meanings that escape our attention. In addition, recognizing that many children with ASD put more *meaning* to written vs. spoken communication, an author should use extra care. All of the considerations related to our spoken vocabulary (pp 19-21), apply to written text.

David's Stories



Within the first few weeks of September, David's placement in a second grade classroom was tenuous. Day-to-day losses in several categories (listed on page 3) were causing the most difficulty (*Social Losses* due to missed meanings; *Performance Losses* related to test taking; *Loss of Control* evidenced by disrespectful responses; and *Loss of Routine* when completing an interrupted assignment). A few loss-related Stories were developed to address these concerns, each matched by a Social Story praising one of David's talents and/or accomplishments and introduced based on the judgment of the educational team.

I have altered the format of David's Stories for this appendix, reducing the size of the text and changing a few illustrations. Restricted permission to copy or revise the Stories in this section for non-profit use is hereby granted.

The Blue Words and the Green Words (Social Losses / missed meanings)

Author's Notes: In the course of the school day, David often made literal interpretations of statements made by others. That being the case, school staff often seemed dishonest and insincere. For example, the first week of music class the students were assigned seats. The following week, the teacher indicated that the students could choose their own seats. All went well, until a student began to misbehave. To remove the distractions that were causing the difficulty, the teacher decided to change his seat. Immediately, David insisted that the music teacher had lied. From David's perspective, the original promise to "choose your own seats" had now been broken. David became very upset and was ultimately removed from class.

The Blue Words and the Green Words was developed to address David's literal interpretations in general. Using logic and mathematics, the Story described why teachers sometimes say less than they mean and introduced the concept of guessing what others mean alongside their statements. The Story closed with the introduction of an activity to generalize what David was learning – an ongoing collection of words and phrases and their intended meanings. In addition, David's teachers were encouraged to try to "say what they mean" and consider that David may occasionally interpret their statements at face value. Considering idioms are a part of the second grade curriculum, the Story was right in line with other classroom activities.

The Blue Words and the Green Words

My name is David. I go to Lincoln School. Sometimes, adults and children may **say** something that is different than what they mean.

Here are some examples:

A teacher might say, "Please sit down." _____ What the teacher means is, "Please sit down in your chair." _____

The principal might say, "Have a good day!" _____ What Mr. Smith really means is, "I hope you enjoy working and playing today, and that you are safe and comfortable." _____

The music teacher may say, "You may sit down wherever you like today." _____ What the music teacher really means is, "As long as you are listening and working and following my directions, you may choose your seat. Otherwise, maybe later during the class, as the adult in charge, I have to choose your seat. If another child needs a new seat to help him or her remember to listen, work, and follow directions, I will need to choose his or her seat." _____

So, it would seem that adults should always say what they **mean**. Teachers and principals are honest people, so why would they say one thing but mean another? The reason adults do this is to save words. They want the children to stay interested, and if they say too many words, some children become bored.

We can count the green words in this Story. These are the words that people say. Then, we can count the blue words in this Story. These are the words that the adults **mean**. We will try to go back and count the green words and the blue words.

There are more blue words than green ones.

Adults are taking a short cut when they **mean** more than they say. For that reason, children try to make guesses about what adults **mean**. If they don't know, they can ask the adult, "What did you **mean** when you said..." The adult will be happy to tell them. That's because the adults at Lincoln want children to know what they **mean**. That is as important as knowing what the teacher said.

On the following pages is my collection of what people say, and what they really **mean**. When we hear what people say, we can write them down in the talk symbol. Then we can guess what people **mean** by writing down our guess in the thought symbol. This is work for a team that includes intelligent second graders, like me!



Smart People Make Mistakes (Performance Losses / test taking)

Author's notes: Some children with ASD become upset when they make a mistake and/or may also be intolerant of the mistakes of others. Rarely is a mistake a planned or predictable event; mistakes upset the routine and proper order of things. They are an announcement that something is not right. Mistakes often arrive with the expectation to re-do, a real inconvenience to a child who may have been planning to engage in a more pleasurable activity.

Spelling tests, then, can be a weekly nightmare - the anxiety of trying to spell every word perfectly coupled with the apprehension of potential error. There are often pre-tests in spelling, and there may be assignments- or even the final spelling test - that do not need to be completed if a student earns 100%. The stakes are high. Spelling is one subject where understanding the meaning of a word is very important; many words sound the same but - there are clues to which spelling is correct based on the way it is used in a sentence. For a child with ASD, spelling is a subject where the rewards for perfection can be high, and the potential for errors, too. Thus, spelling is often not a favorite area of study for many of my students. For this reason, *Smart People Make Mistakes* is a Story that I have used more than once.

Smart People Make Mistakes

My name is David. I go to Lincoln School. Sometimes, I take spelling tests. A spelling test is one way for children to learn which words they know how to spell now, and which words they will know how to spell with more practice.

Very smart people like Thomas Edison (and like me, too) make mistakes. They learn and discover new ideas when they make mistakes. Thomas Edison invented the light bulb, and many other things, too - like toasters and chewing gum. When he

was trying to make the light bulb, he made over **600** mistakes. Each time he made a mistake, he learned what would not work – and got closer to inventing a light bulb that did work. The more mistakes people make, and the more they learn from their mistakes, the smarter they become! Thomas Edison knew this, so when he made mistakes he tried to stay calm so he could learn. Staying calm after making a mistake is an intelligent thing to do.

It's a smart idea to take a spelling test. That way, I can discover all the words I know how to spell now, and those I will know how to spell with more practice. I get smarter each time I master a new spelling word – especially those that are difficult to spell and take longer to learn!



Restating with Respect (Loss of Control / speaking disrespectfully)

Author's Notes: Often, children with ASD respond with words or a tone of voice that is interpreted as disrespectful by others. The concept of respect requires the simultaneous use of many social-cognitive-emotional skills, for example:

1. Feeling frustrated, sad, disappointed, etc. about a situation; while
2. retrieving positive past experiences with the person to whom the statements are directed; with
3. simultaneous consideration of those experiences to temper the choice of words; so that
4. a respectful tone of voice and choice of words is maintained; and
5. this is just a **basic** outline!

Therefore, adults working with children with ASD need to recognize that the child's challenge to "pull this all off" is significantly greater than his classmates. Characteristically, children with ASD often have difficulty:

1. Identifying emotions. Basic emotions, like happy and sad, are mastered easily by some; but others, like frustration and disappointment, require direct instruction and practice.
2. Maintaining control of both negative and positive emotions.
3. Understanding the impact of their statements on others.



Teaching a child to respond respectfully is a process, necessitating that adults remain calm and keep their feelings in control - viewing their role as instructional - in this case, teaching "social." This requires an active understanding of the child's point of view. Therefore, to teach respect to a child with ASD requires those working on his/her behalf to model the same regard. In the face of a disagreement or misunderstanding, a child cannot be asked to maintain a tone and words that are calm and controlled if the adults who surround him are unable to "pull it off" themselves.

For this Story, the adults on David's team were asked to do the following in response to a disrespectful statement:

1. Cower or flinch and quietly say/or demonstrate "Ouch."
2. Provide an opportunity to correct, beginning with the child's name and "please," as in "David, please restate with respect."
3. Draw concrete attention (Respect Board, Respect Box) respectful deeds, statements, etc. by posting them (Respect Board) or collecting them in the Story or writing them down to place in the Respect Box.

Restating with Respect

This is an article about talking with respect. Talking with respect is using a calm, controlled tone of voice with cooperative words. When working and playing with adults, classmates, and friends, talking with respect is very important. That way, everyone feels comfortable.

Adults in charge of me at school notice those situations where I have talked with respect. Once I had to wait for a while before getting a YoYo, and I listened to the adult and answered her respectfully, even though I may have been a little disappointed. At a book fair, I had to put a book back. I listened to the adult volunteer and answered respectfully, and left with two books instead of three. Keeping my emotions under my control is a smart and friendly thing to do.

Here are other respectful things I have said and done at Lincoln:

1. _____
2. _____
3. _____

Sometimes, all children need an adult to help them restate their words and feelings with respect. They may tell others what they are thinking and feeling, which is okay, but they use a tone of voice or words that hurt or insult. This is a mistake. Then that person may feel hurt, insulted, or uncomfortable. To help children know for sure when this has happened, they may cringe and say "OUCH!", or they may say respectfully, "Please restate for respect."

Sometimes, it is easy to speak respectfully. Usually, it is easier for children to speak with respect when they are feeling happy, calm, or comfortable. Most children find it is a little more difficult to speak with respect when they are feeling frustrated, sad, or uncomfortable. These feelings are okay. It is also okay to let others know about these thoughts and feelings. As children grow older, though, it's important to learn how to share these thoughts and feelings by choosing respectful words and tone of voice.

All children make mistakes with respect sometimes. This is called "being disrespectful." Children learn to apologize, and how to re-state their thoughts and feelings. In this case, restate means saying it again, with respect. Sometimes, they can just repeat what they just said, but with an in-control voice. Sometimes, they can choose other words, too.

Adults at Lincoln are so impressed with those times that I have used respect with my friends, classmates, and adults. It's important to be respectful throughout the school day. It's also important to let others know what I am thinking or feeling. The adults at Lincoln will work with me as a team to learn to restate for respect. That way, everyone will be comfortable working and learning together.



We can collect the respectful things that I say and do in this list. Or, we can write them on another piece of paper and put them in my Respect Box. It is my choice:

1. _____
2. _____
3. _____

Adults in charge of me will be watching for those times when, even though it may be a challenge, I choose respectful words and tone of voice. They may decide to fill out a Respect Others form like the one on the following page. Here's how it works:

1. I say or do something that shows respect to others.
2. An adult in charge of me decides to let others know about it.
3. The adult fills out the Respect Others form, describing what I said or did.
4. I can show the form to Mr. Smith. He feels happy and makes a copy that he can keep, and one for my mom and dad.
5. Then, Mr. Smith puts it up on the Respect Board for all to see!

AOK Ways to Finish My Work at Lincoln School (Loss of Routine / completing interrupted work)

Author's Notes: David is not the first child I have encountered who prefers to finish one task before proceeding to the next. To leave an activity requires re-sequencing: a spelling assignment may be interrupted, and, not only that, completed during a time usually set aside for mathematics. Suddenly, everything is out of its natural order. Add to that the frustration of the given assignment if it is one that is difficult, and emotions can quickly escalate.

The original copy of AOK Ways to Finish My Work at Lincoln School appears on the following page. I have only added the arrows in the accompanying illustration, to further emphasize the process of moving through what may be a very challenging situation.



A.O.K. Ways to Finish My Work at Lincoln School

My name is David. I am an awesome student at Lincoln School. Most of the time, it is important that children finish their work.



One Way: One way to finish my work is to finish it all at one time. This means that I start it, work on it, and finish it. Then, I go to another activity.



Another Way: The other way to finish my work at Lincoln School is just as good as the first. Here's what you do:

1. **START WORKING** and then...
2. **GO DO SOMETHING ELSE** and then...
3. **COME BACK TO THE WORK, AND WORK SOME MORE** and keep doing that until the work is finished!

Second graders often have to do their work **ANOTHER WAY** because they are older, busier, and have many things to do. Adults tell children if it is **AOK** to do work **ANOTHER WAY**.

Appendix C: Additional Ideas

Appendix C contains two new ideas to help students with ASD learn from their losses as they encounter life's setbacks, *The Suitcase Curriculum: Traveling through Life* and *The Worry Cup*.



The Suitcase Curriculum: Traveling through Life

- Carol Gray, Wilma Wallis, & Mary Ann VanHouzen

Each year, students ages 12 - 18 with autism spectrum disorders (ASD) in the Ottawa Area Intermediate School District (OAISD) in Michigan have the opportunity to attend a social understanding group. The OAISD is an area encompassing many school districts. The annual program was initiated several years ago to meet the needs of secondary students who had limited opportunity to meet peers with similar talents, interests, and challenges within their home school districts. This year 32 students attended. Meeting for five weeks, the program gave students an opportunity to share experiences, participate in a program to build social concepts and skills, and have fun. Instructors for the program included three consultants to students with ASD and a social worker, with support from several instructional assistants.

There is a challenge each year to find a curriculum that will address relevant topics in an interesting and personally meaningful way, especially within the restrictions of available time. Prior to the first class, the instructors, parents, and a few students met to identify topics for the program, among them, emotion regulation and social problem-solving skills. These ideas were built into a curriculum based on a vintage suitcase with destination decals (above).

Travel was used as an analogy throughout the program, emphasizing how to "move through" uncomfortable life destinations. There was a "topic destination" each week that identified one of five steps to effectively work through life's unexpected setbacks: Week 1: *Know the People on My Team*; Week 2: *Make a Plan*; Week 3: *Look for and Provide Relevant Clues*; Week 4: *Coping Mechanisms*; and Week 5: *Pack Well - Put it All Together*.

An instructor opened each class with a predictable dialogue: *This is my suitcase. It is vintage; it is over fifty years old. It is covered with destination decals; places it has traveled through for a short period of time. I am vintage. I am over fifty years old. In my life I have traveled through many destinations. I have visited places. I have had social destinations, like a birthday party. I have had emotional destinations, times when I have been happy or sad. What other kinds of destinations are there in life?* Students contributed more ideas each week in response to this question, including: thinking destinations (imagination), spiritual destinations, and destinations on the Internet. Provided with an interesting frame of reference, they responded with insights well beyond their years.

Visual strategies and personalized materials kept things interesting. The curriculum was enhanced by a PowerPoint presentation that added color and movement. Each student had their own "suitcase," a box with an attached lid. Related activities were completed each week - with notes packed inside the suitcase - along with a list of personal strengths and talents for future reference. To give each course destination personal practicality, students created a "destination decal" and pasted it to their box. At the close of the course, each student left with a life suitcase, decorated with personal decals to recall in tough times and packed with information to use to get through them.

The Worry Cup - Ben Hoekman

Ben Hoekman is a young man with lots of talent and great ideas, as evidenced by his strategy for staying calm and keeping in control, *The Worry Cup*. His original article appears on the following page.

The worry cup

The worry cup we used for worrying about things. Most of the things I used it for was fire drills, (which I still don't like!) We prayed about them, and after school we pulled them out and talked about them. If we had any we didn't need, then we'd throw them away.

If you'd like to, you or your children can pick a special cup they like. Write the worries on pieces of paper, and put them in the worry cup. You can even pray about them. When you or your children get home from work or school, then talk about them. And if there are any that you don't need, then throw them away.

I kept my worry cup by the door and before school, I'd put my worries in the cup. You or your children can find a place for the cup. Follow all these directions, and you and your children should find that you don't have to be worried about things.

The End

By: ~~Ben~~ Hochman, age 8.