## Some Information about Autism Spectrum Disorder

The majority of the world's population has the ability to communicate and understand social phenomena; however, social cognition and the ability to communicate can be absent or deficient in varying degrees in people with ASD (Autism Spectrum Disorder). ASD individuals have difficulty integrating various pieces of information;, this decreases behavioral flexibility and the ability to think abstractly (Frith, 1989; Frith & Happé, 1994a). The ability to think abstractly, allows people to interpret things they read and hear beyond a literal level: this includes the ability to enjoy humor and understand analogies. For an individual with ASD, everyday life is inundated with social stress: from the exposure to confusing customs and complicated linguistics of those around them.

## Carol Gray:

## An Engineer of Literature for ASD Children

Literature has been a crucial tool to promote social learning and understanding throughout history. Children with ASD often lack these basic social concepts because there are few literary works that are written from their perspective. This leaves little that they may relate to and gain understanding from. It is fortunate that within the past decade, some progress has been made in this area. Carol Gray is at the forefront of this advancement of literature. She has engineered an effective formula for adapting literature to the ASD individual's unique perspective. Carol Gray has shared with the world how this formula may address ways to help ASD children learn to comprehend literature, to escape from ridicule of bullies, to respond correctly to social situations, to do routine tasks such as brushing teeth and getting dressed independently, to deal with difficult issues such as death and loss, and to do many other things that help children with ASD to effectively engage in a social world.

Carol Gray was born in 1952 in Brookings, South Dakota, when public special education was not a widely available or a mandatory public service. A popular solution during this time for children with severe mental disabilities or anyone with a significant

psychological abnormality was long-term placement into a mental institution. Societal integration was considered too dangerous for the individual and society. Autism, from its discovery in 1944 through the early 1970's, was most commonly thought to be an emotional disorder caused by a cold mother who did not properly show affection to her child, and often treatment included putting the mother into psychiatric counseling<sup>1</sup>. Although advancements in psychotropic treatments were just beginning to allow many patients to be released from mental hospitals, the level of public understanding of mental abnormality would take many years to rise above fear and pity.

Carol was fortunate to have had the opportunity to interact with mentally ill people on a daily basis in her childhood. Her father was the Director of Community Relations at Northville State Hospital, for the mentally ill. Carol's mother would drive her father to and from work everyday because her family, like most families of the 1950's, only owned one car. Carol and her two older sisters would have to go with their mother to pick their father up from work. Carol remembers enthusiastically,

"She [their mother] would encourage one of us to go upstairs to dad's office to get him. That was a scary proposition, because it meant walking past people with schizophrenia and very severe mental illnesses who would occasionally be on those steps. My sisters absolutely refused to go; I was always quick to volunteer. I took delight in being the youngest and also the one who was not afraid of the people on the steps. I liked them and gradually got to know some of them. As they would call out random phrases or make unique or unexpected gestures, I would smile and say, 'Hello'." (Interview, 2003)

In addition to her extensive early childhood experience with people with severe mental abnormality, Carol's relationship with her father shaped her personality. She describes her father as "...a very unique and socially awkward character" (Interview, 2003). Similarly, ASD individuals are characterized by social

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<sup>&</sup>lt;sup>1</sup> (www.autistickids.org/autinfo1.html, para. 19) (http://www.fanlight.com/catalog/films/346\_rm.shtml)

awkwardness. Carol is likely to have developed skills to effectively communicate with ASD individuals through growing up with a father who shared a degree of their characteristic social awkwardness. (Interview, 2003)

Carol entered college during the advanced stages of the Civil Rights Movement. Minorities were quickly gaining the rights and privileges held previously by only the majority. Carol, eager to contribute to this new society, finished her undergraduate degree in psychology and child development from Central Michigan University in three years instead of four. During the short time she was there, she met her future husband, Brian, while working for a phone in crisis intervention center on campus. In 1974, they were married.

A year later, PL 94-142 was passed, creating a need for special educators. This law made public special education free and appropriate for all children with disabilities. More specifically it stated that the disabled student must receive nondiscriminatory evaluation, an individualized education program (IEP), a least restrictive learning environment, due process of legal procedures to ensure the fairness of educational decisions, and inclusion of parental participation in the development of the IEP for their child.

Carol soon achieved a variety of endorsements in special education including mentally impaired, emotionally impaired, learning impaired, and autistic impaired from Grand Valley State University and Western Michigan University. She began to teach children with ASD at Jenison High School in

Michigan, later establishing the international newsletter Morning News, now called the Jenison Autism Journal, in 1988<sup>2</sup>.

For many years, Carol focused on trying to change her ASD students' behaviors into a less socially awkward form through behavior modification, the most accepted form of changing behaviors of children with ASD. Behavior modification, although effective in improving behavior of ASD individuals, does not consider behavior at the cognitive level3. Behaviors often change through behavioral modification, but without continued reinforcement deeper cognitive processing, these behaviors often fade gradually. Carol got an idea about how to address the cognitive processes of ASD individuals by a conversation she had with a fourteen year old autistic boy. This boy spent part of the day in a mainstream classroom and was answering every question that the teacher asked the class, without being called on first. Carol wrote a story for him that described proper question answering in the classroom. This story helped him understand why you must raise your hand and be called on before you can answer a question (Bezark, 2003) (Interview, 2003). The success of this informal experiment, encouraged Carol to expand this use of literature into what she began calling Social Stories. Through trial and error, Carol began to discover the structural factors that led to a successful story. discovered that she could write stories on innumerable topics including simple everyday tasks such as brushing one's teeth, conversation skills and comprehension, appropriate social behavior, conflict resolution, and how to deal with bullying.

After about one year of writing Social Stories for her students, Carol developed a formula for effective Social Stories. This formula is intended to

<sup>2</sup> www.thegraycenter.org

<sup>3</sup> http://www.lupinfo.com/encyclopedia/B/behavrTher.html

create literature that children with ASD can read and comprehend. The goal is an improvement in social cognition of a certain topic. Gray defines a Social Story as a process that results in a product for an individual with Autism Spectrum Disorder and those working on their behalf (Gray, 2000). The basic version of the formula uses four basic sentence types: descriptive, perspective, affirmative, and directive, in the ratio of 0-1 directive sentence for every 2-5 descriptive, perspective, and/or affirmative sentences (Gray, 2000). In addition to the formula, Carol has made guidelines for effectively writing and implementing a Social Story. The guidelines are based on the learning characteristics of children with ASD. One guideline, for example, is that when a Social Story is made to address a negative behavior, it must be written in third person in order to avoid placing blame on the individual. However, in other Social Stories use of the first person perspective of the child it is being written for should be used with only the occasional third person statement. A Social Story must always be implemented in a calm, reassuring way to promote interest in the story and social learning. When all teachers are informed about that a particular Social Story has been made for a student, they become more prepared to deal with the behavior of their student<sup>4</sup>.

Two years later after perfecting the Social Story formula and guidelines and piloting it on her own students, in April 1993, she co-authored the first article describing Social Stories titled *Improving Responses of Students with Autism and Accurate Social Information* published in Focus on Autistic Behavior. Later that year, Carol published a book called The Original Social Story Book. After teaching Jenison High School students taking sociology or psychology how to

<sup>&</sup>lt;sup>4</sup> For a more detailed description of the Social Story Formula go to www.thegraycenter.org

make social stories, Carol edited and compiled a book of their stories titled New Note of Print Social Stories in 1994. It is now under the title, The New Illustrated Social Story Book (revised 2000). The Social Stories in this book are for children with ASD from elementary to high school grades. Carol Gray received the distinguished Barbara Lipinski Award in 1995 for her international contribution to the education and welfare of children with ASD. In 2002, Carol wrote and published My Social Stories Book, a book of Social Stories for children aged two to six. These Social Stories incorporated the use of Social Story Sets, a collection of very short stories related to one topic that share a single illustration. The purpose of including Social Story Sets was in consideration of the attention span of younger children (Gray, 2003).

The universality across cultures of Social Stories gained world-wide recognition through the seasonal publication Morning News. Carol Gray founded the nonprofit organization called Gray Center for Social Learning and Understanding in the early 1990's, and was soon traveling to various countries to give presentations on her Social Story formula. When asked about the different reactions she has had to her social stories in different parts of the world, as well as how ASD individuals are taught in different parts of the world, Carol replied that pre-existing attitudes that people bring to their work on behalf of children with ASD can make Social Stories take a variety of profiles as they are interpreted by different minds. Attitude, she says, "...sorts people who can write Social Stories, from those who just can't. I am glad the former far outnumber the latter. In terms of Social Stories, and the education of children with ASD, the attitude differences far exceed the cultural contrasts" (Interview, 2003). Only a small amount of

research has been done on the effectiveness of Social Stories, but this research has suggested Social Stories can be highly effective for long-term improvement in behavior<sup>3</sup>.

The question of how to discipline a child with ASD is commonly answered incorrectly by mainstream teachers who know little about ASD. Gray believes that Social Stories help improve teacher perspectives on discipline of children with ASD. Many behaviors of ASD children (i.e. speaking out of turn, jumping up and running out of the classroom, pushing, making strange verbal noises randomly) are too often confused as bad, intentional behaviors that should be dealt with through punishment. More often than not these behaviors are the result of misunderstandings between the teacher's perspective and perspective of the child with ASD. Carol Gray's Social Stories provide a medium to address discipline issues in a way that is understandable for both the student and the teacher. Social Stories should never be used as a punishment because this could create a generalized dislike of all Social Stories.

While many mainstream teachers are often unprepared for some behaviors of children with ASD, the child with ASD is often disturbed by inconsistencies in the way the teacher uses discipline. Carol Gray is very concerned about how to model effective conflict resolutions. She says, "...many of our traditional teaching responses, when viewed from the perspective of a child with ASD actually demonstrate inappropriate behavior" (Interview, 2003). Sometimes, for example, a teacher might interrupt students that are talking, and interrupting could be a behavior an ASD child's special education teacher may be trying to discourage. She has developed a presentation titled Correct,

<sup>&</sup>lt;sup>5</sup> A list of research that has been done on Social Stories is found at www.thegraycenter.org/Social Stories.htm#Social%20Story%20research%20articles

<u>Confront, Concede, or Teach?</u> to address this complex issue. Social Stories, Gray says, teach over correcting, confronting, or conceding.

Social Stories have been highly effective because of the way they address deficits in ASD individuals' theory of mind. The abilities to predict the behavior of others, relate to others effectively, and empathize are collectively called the theory of mind of an individual (Baron-Cohen, 1995b). During the 1980's through the present, a large amount of theory of mind research has been conducted that has given insight into the autistic perspective of the world. Research has shown that autistic individuals have severe deficits in communication, social cognition, or/and behavioral flexibility that are detected before the age of three (APA, 1994). These deficits interfere with the development of a normal theory of mind in an individual with autism. These deficits in an ASD individual's theory of mind that make the ASD individual a socially awkward character.

Comprehension of literature and the rapid information exchange that occurs in conversation, with deficits in a theory of mind, would be difficult. Carol Gray developed and published her book <u>Comic Strip Conversations</u> in 1994 in the effort to help ASD children understand conversation and comprehend literature. Incorporating the use of eight basic symbols for conversation skills as well as the use of different colors to represent different emotions in a concrete way, Comic Strip Conversations are defined as "...a conversation between two or more people which incorporates the use of simple drawings" (Gray, 1994). Often, in conversation, people leave out obvious information and assume the person they are talking to know this information already. ASD children have trouble inferring the meaning of a conversation beyond its literal value. Comic

Strip Conversations help to show each progression of a conversation in a different box, when to use certain conversation skills such as talk and listen, and possible outcomes of a conversation. This is particularly useful with helping an individual with ASD come up with solutions to social conflicts such as bullying. ASD children often understand what happened in a story, but struggle to understand specifically who the main characters are and the role of the characters in the story (Interview, 2003). This is analogous to knowing what a puzzle is supposed to look like, but not being able to put its pieces together. Carol suggests that Comic Strip Conversations can be used to help ASD children comprehend literature by identifying the main characters and what those characters said and did through a series of pictures segmented into a progression of easily distinguished boxes (Interview, 2003).

The success of the systematic, methodological approach to literature that Carol Gray has created Social Stories through is a testament to what meaningful creation and use of literature may do for society. All children's current abilities, interests, and issues may be nurtured to fruition through purposeful literature. The great contrast between the deficit social perspective and the social perspective demonstrates the importance of not taking social understanding and social learning for granted. It is not surprising that, considering the universality of the need for social learning and understanding, Carol would like to someday expand her creative endeavors to writing purposeful books for all children (Interview, 2003). The potential reach of her approach to literature is inspiring, encouraging, and including of all people.

Bezark, Mary J. 2003. Mild autism spawns new approaches. www.chicagotribune.com/business/custom/educationtoday/chi-0307130324jul13,0,1055529.story.