Self-Advocacy and Autism

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Abstract

Self-advocacy skills are essential for an individual with a disability to ensure they can be independent and feel a sense of belonging in their community and family. Therapists and teachers can help individuals to become aware of their strengths and learn to feel comfortable with whom they are. Families can learn how to support and foster self awareness therefore increasing an individual’s ability to self-advocate. The characteristics of autism that affect an individual’s ability to advocate for themselves, as well as how the family can be affected and have an influence on the individual’s growth will be discussed. The history of self-advocacy will be touched on, as well as Alfred Adler’s belief of social interest and how it fits well with an individual’s success with self-advocacy. Other psychotherapeutic approaches that fit well with the Adlerian approach will also be discussed.
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Self-Advocacy and Autism

Autism is on the rise and continues to make headline news regularly. Many families and individuals are affected by this neurological disorder that affects all areas of life. People with autism are most affected in the area of social communication. Social communication includes an individual’s ability to effectively communicate, enjoy the company of others, and understand the perspectives and feelings of others. Often people with autism need direct instruction and skill building to effectively live in a society that has limited tolerance for odd, quirky behaviors and interactions.

With this increase there is also a growing need for therapists who understand autism. Families and individuals seek out therapeutic support and help with skill building and emotional challenges they face due to the unique needs of the individual. For many people, especially those identified with autism at an early age, the families become the advocate for services and change. As the person grows, it is imperative that they begin to gain skills to advocate for themselves. Therapists can support families and individuals by building on skills. One of these skills is for the individual to be a self advocate. For an individual to be an effective self advocate, they need to first have awareness of themselves. Alfred Adler believed that social interest was the basis for every human being to feel a sense of belonging in their family, community and intimate relationships (Oberst & Stewart, 2003). All people are social beings; however individuals with autism find it challenging to fit into the social rules that have been set. With the ability to advocate for their unique needs they will likely find themselves having more success with finding social interest and a sense of belonging.

Self-advocacy skills are essential for an individual with a disability to be independent and feel a sense of belonging in their community and family. Therapists and teachers can help individuals learn such skills and help families learn how to support and foster advocacy skills.
This paper will further discuss the characteristics of autism that affect a person’s ability to advocate for themselves, as well as how the family can be affected and have an influence on the person’s growth. Self-advocacy has a history that will be discussed and how Alfred Adler’s beliefs fit well with the striving for success and social interest of the individual. Other psychotherapeutic approaches that fit well with the Adlerian approach and can be effective in supporting positive movement will also be discussed.

**Autism Spectrum Disorder**

What is an Autism Spectrum Disorder? The Diagnostic and Statistical Manual – IV (DSM – IV TR, 2000) describes autism as a Pervasive Developmental Disorder (PDD) that is “characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities” (p. 69). There are different levels of autism based on the person’s developmental and cognitive levels. No matter what level someone is at they are fully capable of being able to advocate for themselves. For this paper the author will be using the word autism to describe a person who could be at any level of the spectrum unless specifically mentioned.

All three areas of PDDs affect the person’s ability to be an effective self-advocate. Specifically the areas that affect them the most are related to the use and understanding of non-verbal behaviors (eye contact, facial expressions, gestures and body language), inability to develop appropriate peer relationships and lacking in social and emotional reciprocity (DSM-IV). All of these are social skills that are challenging for people with autism and can have a devastating effect on all aspects of their lives. Social skills provide the person with the ability to communicate effectively in a social environment without fear or hesitation and without being self-conscious. It is the ability to engage in conversations regardless of how well you know the other person or persons. Areas that are affected by impairments in social skill development
include peer relationships, instructor/employer relationships, family relationships, being able to navigate the community, and various employment or volunteer environments (Freedman, 2010). Self-advocacy is especially affected by the impairment of social skills.

Theory of Mind is associated with individuals with autism and should be understood in order for a therapist to effectively help the client to make positive change. Theory of mind is the ability to understand the intentions of others, to understand how their behaviors affect others and how to participate and engage in reciprocal social and communication skills (Attwood, 2001). Tony Attwood (1998) believes that individuals develop an understanding of other people’s thoughts, feelings and beliefs that then influence their behavior, around the age of four years. People with autism lack theory of mind and the ability to understand the perspectives of others. Without this ability to understand the perspective of others it is difficult for them to have effective reciprocal interactions and relationships.

Sarita Freedman (2010), stated that “psychologically, self awareness is key in the development of ‘self’ because it is the precursor to awareness of others” (p. 47). If someone does not understand themselves and their characteristics it is impossible to identify those same characteristics in others. In order for a person to be self aware, they need to first accept who they are. This can be very difficult and many individuals and families struggle to accept the person for who they are. Without self awareness it is difficult for the person to act on the thoughts, feelings and perspectives of themselves and others automatically and deliberately in a fluid movement (Perry, 2009). Direct and focused instruction can help the individual become more self aware therefore beginning to have some insight into the perspectives of others. Freedman (2010) believes that the individual needs to first accept that they have a disability, be willing to disclose they have a disability, have an interest in learning about their challenges and strengths, be willing to ask for help and work with therapists and other professionals.
Accepting oneself helps the person know that they are not alone or crazy. They are able to feel a sense of belonging to a group of others like them and they can feel proud of whom they are. Acceptance helps the person understand who they are what their strengths and challenges are and ultimately they will be able to self advocate for their needs. One of the scariest pieces of accepting who they are as an individual is disclosure with others. Disclosure can be a great way to gain an understanding and perspective of others. It can deepen relationships and trust, fostering a deeper sense of belonging. It can also be risky not knowing how others will accept the information they gain. For people with autism this can be especially challenging because they have difficulty picking up on the social cues including approval or disapproval and knowing when to stop or continue with the information being disclosed. Ultimately, self awareness leads to self acceptance and gives the individual with autism tools to advocate for their needs.

**Family and Autism**

Everyone has a family; however, each is unique due to the unique needs that each individual in the family brings to the collective group. Many factors influence the characteristics of each family. There are similarities and differences with other families, and for many, one similarity is having a person or persons with autism as part of the family. People with autism have strengths that include excellent long-term memory, strong interest and knowledge for particular subjects. Some challenges include limited topics of conversation, inability to know how to interact with others appropriately, and sensory issues. Challenges can also be strengths and some of their strengths can make it challenging to function in our society. Families tend to see the challenges easier than the strengths of the individual.

People with autism often need varying levels of support depending on their strengths, challenges and age. Families tend to struggle to see the amount of support needed. Some are over protective and others are unsure of what kind of support is best. Families tend to lose track
of what is typical development and what part of the autism is affecting the person’s ability to function. Families have increased protection of someone when they are younger, but have a hard time knowing when to let go of supports as the individual gets older. As individuals become adolescents the families may need reminders that some of the behaviors and challenges are typical for their child’s age. In order for someone with autism to gain self-advocacy skills the families need to accept them and help them to learn to accept themselves.

Just as individuals need to have awareness and acceptance for their unique needs, families also need to have awareness and accept the individual for who they are. Some families embrace their child and the autism by learning all they can about autism and how they can support them. Other families find it challenging to accept that their child has autism. Many families experience guilt, shame and denial. Some families are better able to accept the person and the autism, which makes things easier for everyone. Families grieve each time their child does not reach milestones as a typical child might. Such milestones include entry into middle school, high school or college, getting a drivers license, going on dates, getting invited to birthday parties or sleepovers, attending dances and living independently. Families who do not accept the individual make it very challenging for the individual to accept themselves.

Many individuals have taken or are taking medications for anxiety, depression and other needs. As Goldenberg & Goldenberg (2008, p. 387) said, “The interventions are about setting limited goals and helping to minimize the symptoms, rather than cure the individual.” Families of people with autism across the country and world are trying to find the cure to autism. At this point in time, there is no cure for this neurobiological condition. Therapy can help families to understand the symptoms and give them a safe place to vent their concerns and frustrations. Therapy is also a place for them to learn more about the symptoms and how to support the person with autism and the other family members.
Within the family, siblings may be one of the most important relationships people with autism can have (Conway & Meyer, 2008). A sibling relationship is typically one of the longest lasting relationships any individual will have. However, when one sibling has a disability the relationship can be drastically different. Aksoy and Bercin Yildirim (2008) found that non-disabled children do not see their disabled sibling’s disability as a challenge to them. The attitude of acceptance was more positive toward their own sibling with a disability than those who do not have a disabled sibling. However, the authors found that children with siblings who have autism displayed more negative ideas about sibling relationships, more loneliness and more concerns about their sibling’s future. Orsmond and Seltzer (2007) found similar results in adult relationships when a sibling had autism. The results found that siblings of brothers or sister with autism had less contact, experienced lower levels of positive affect, and felt more pessimistic about their brother or sisters future. However, they did report that their relationships with their parents were more positively affected as a result of having a sibling with autism.

Having a sibling with autism not only makes it difficult to have a positive relationship, but also changes the way the family relationships develop. Non-disabled siblings often worry about how they are going to manage and care for their disabled sibling after their parents are gone. Such perspectives and levels of acceptance of the person with autism can directly affect the person’s ability to accept themselves. It is important to look at the perspectives of individual family members and offer encouragement to be imperfect, but supportive toward the family member with autism.

As stated earlier, the ability to accept occurs when there is understanding. With the steady and rapid increase in the number of people with autism there is much debate about what causes autism. Is it genetics or environmental triggers or is it a combination of both? Goin-Kochel and Myers (2005) looked at the parental perceptions of what caused their child to have
autism. They found that about half the parents felt the cause was genetic-based and the other half felt it was environmental. Of these, some felt it was maybe a combination of both, but could not be sure.

There has been other research that has looked at the causes of autism, even well before it was being recognized in the United States. In 1975, Harper and Williams conducted a study that looked at whether children were more likely to have had autism at birth or if they developed the disorder after a normal period of development. They found that parents described their child’s onset of autism as either being at birth or after a physical or psychological trauma. Either way there seems to be a difference in the look of those who seem to have it at birth and those who acquire it after a period of normal development.

No matter how parents report when they recognized that their child developed autism, the important factor for therapists to be aware of is that the parents perspective will have an impact on how the child and the rest of the family handles and accepts the family member with autism. As a therapist, it will be essential to gather early recollections and uncover mistaken beliefs so the parents and person with autism can all more forward toward their goals. Ansbacher and Ansbacher (1956) stated that children are influenced by their situations early on and the situation influences the style of life they will have. People with autism cannot change that they have autism, but they can learn to cope with their challenges. It would then stand to reason that positive support and encouragement can improve the life and relationships of a person with autism within the family and then with relationships outside of the immediate family. When families accept a person with autism for who they are it will encourage them to accept themselves therefore making it easier to advocate for them.
Self-Advocacy

“Self-advocacy is related to the ability to determine how we would like to live our life, make life choices that are meaningful and express likes and dislikes” (Lentz, 2004, p. 84). The movement for self-advocacy began in Sweden in 1960 (Caldwell, 2010). According to Buchanan & Walmsley (2006) and Gilmartin & Slevin (2009), it is considered unique to the twentieth century. In the 1970s and 1980s the self-advocacy movement grew in the United States with children with disabilities being able to attend public school and receive reasonable accommodations (Ward & Meyer, 1999). Such a movement grew into the passage of the Americans with Disabilities Act (Ward & Meyer) and the formation of organizations supporting and encouraging self-advocacy (Caldwell). Such groups provided people with developmental disabilities their first and most consistent opportunities to develop leadership skills. As the push toward independence and alternatives to institutions developed, it was believed that self-advocacy was about being able to speak for yourself, to make your own decisions, to know your rights, and to stick up for your rights (Ward & Meyer). This also includes having someone speak up for those who are unable to speak for themselves.

In 1990, the first national self-advocacy conference was held in Colorado leading to the formation of organizations such as Self Advocates Becoming Empowered (SABE) (Caldwell, 2010). Such groups continue to exist and there are more than 800 chapters across the United States and 43 countries. Locally, the Arc Greater Twin Cities is an organization that supports individuals with intellectual and developmental disabilities and their families, and works to ensure they have the opportunities to reach their goals (Arc Greater Twin Cities, n. d.). Other organizations that support and encourage self-advocacy for individuals with disabilities are locally The Autism Society of Minnesota and Metropolitan Center for Independent Living and nationally The National Autism Society.
“Self-advocacy is the primary social movement in the developmental/mental health disability community today” (ACT: Advocating Change Together). People with autism are often at a disadvantage compared to their neurotypical peers. However, there is hope and they can achieve all their goals. Ed Turner (2007) talked about his experience and how he uses self-advocacy to meet life’s many challenges. Some advice that he gives is to not ignore the wrong that has occurred but to look at it positively and take the opportunity to make a change. He believes that self advocates are not afraid, but are confident and know that blaming others will not end positively. Ultimately he believes that “self-advocacy allows all who choose it, to navigate life under their own terms” (p. 70).

A person does not quickly gain the ability to advocate for themselves, but they continue to grow with time and acceptance of their strengths and challenges. They can gain skills in many ways such as asking for help, knowing who to ask for help, researching or reading about their disability and others who have similar characteristics, completing assessments and interest inventories and learning how to use their special talents and interests to achieve great things.

**Alfred Adler and Social Interest**

Gemeinschaftsgefühl or Social Interest according to Ansbacher and Ansbacher (1956) is an innate part of the individual, but needs to be developed. It starts with social relations. Social relations begin immediately following birth and some may say it begins with the fetus, pre-birth. It is up to the child as to when social interest and understanding will develop. However, it can be influenced by the environment, the internal drive of the child, educational influences and influences of the family. Ansbacher and Ansbacher (1956) also mention that it is influenced by the experience of the individual’s body and how they interpret what is happening. For persons with autism, they are already challenged by their inability to understand their environment and recognize or understand what they are experiencing internally, let alone recognize it in others.
Ansbacher and Ansbacher (1956) expressed how important the mother is to the healthy development of the child. Bruno Bettelheim during the 1940’s to the 1970’s (Rudy, About Us: Psychology, 2006) blamed mothers for causing their children to have autism because they didn’t love and hug them enough. He referred to these mothers as ‘refrigerator mothers’. One similarity between the refrigerator moms and the mothers that Ansbacher and Ansbacher (1956) are describing is the need to overcompensate for their child’s difficulties with social relations. One of the challenges people with autism have is their inability to understand the feelings and emotions and perspective of others, or lacking theory of mind. This does not mean that individuals with autism are unable to have empathy; it just means they have trouble understanding that others think and feel differently than they do. Through direct instruction and therapy, individuals with autism can learn to read the body language and social cues of others in order to understand the other person. Ansbacher and Ansbacher said that the ability to identify others must be trained and can be, as long as the person feels they “are part of the whole” (p. 136).

Language also plays a large part in the social life of each person. Ansbacher and Ansbacher (1956) said that language would not be necessary if it weren’t for the social life of individuals. Language and logic have lead to the overall ‘rules of the game’ which in turn is developed as a result of social interest among the human race. Language and communication with persons with autism is a challenge. Not necessarily with the articulation, but with the inferential and abstract parts of communication.

Having social interest means feeling like part of a family, a group, a couple, and the human community. Social interest means to participate, to contribute, to share, to feel accepted, appreciated, and loved as well as accept, appreciate and love other people. As previously mentioned, this can be very challenging for someone who lacks theory of mind. Social interest is
a feeling of belonging to others and not being “outside” (Oberst & Stewart, 2003, p. 12, 17-19). Leak and Leak (2006) said that social interest is the main characteristic of each person and is involved in all their actions and is required for healthy functioning.

Adler believed that social interest was the driving force for the three life tasks: friendship, love and work. Without social interest and success in the life tasks it is difficult for an individual to meet life’s challenges and feel a sense of belonging, safety and security. Eva Dreikurs Ferguson (2010) believed that all humans need to feel a sense of belonging (p. 1). Mental health improves when an individual feels a sense of belonging. However, when social interest and belonging are missing an individual struggles with effective self-advocacy skills. In relation to autism, advocating is effectively communicating for one’s self and can be either positive or negative, using verbal and non-verbal behaviors. Such behaviors can be expected or unexpected (scripting or repeating phrases/words, repetitive behaviors, quick and odd movements, disfluent verbal thoughts, etc) and can affect the person’s ability to effectively advocate their unique needs.

“To see with the eyes of another, to hear with the ears of another and to feel with the heart of another” (Carlson, Watts & Maniacci, p. 67). This is such a bold statement that speaks to the challenges that individuals with autism face. Adler was talking about taking the perspectives of others and putting yourself in the shoes of another person. This can also be called theory of mind. As stated earlier, individuals with autism have a very difficult time understanding the perspectives of others and lack theory of mind. Adler believed that when a person is able to understand the perspectives of others they have a social interest. Individuals with autism have the capacity to be empathetic towards others, but lack the ability to fully understand the other person’s perspective.
A therapist is able to help clients to better understand or be aware that others have different perspectives than them. It is believed that a therapist with social interest has the courage to be imperfect, and they are genuine. Adlerian therapy consists of many components. It is based on a growth model, stressing the client’s positive capacities to live fully in society. Adlerian therapy stresses that life goals give direction to our behaviors and that all behavior is purposeful and goal oriented. We are all motivated by social interest and a sense of belonging and having a place in society. Feelings of inferiority serve as creativity, motivating people to strive for mastery, superiority and perfection. Everything individuals do is guided by their unique lifestyles. Actual birth order is not as important as how the individual interprets his/her role in the family (Corey, 2009).

Therapists can help by encouraging people with autism to make changes. Karasu and Bellak, (1994) talked about how a client’s thoughts, feelings and behavior reflect who they are. Each client is unique and has strengths and challenges that are displayed by their actions and reactions to others and situations.

Much like Adler, Erik Erikson talked about the development of the whole person resulting from well developed social experiences. His basis was that through social interactions, an individual develops a sense of self. This sense of self, or ego identity, is a building block for learning new things (Cherry, n. d.). Erikson believed that this was all part of the first stage in development. He believed that people go through many stages during their life time. He felt that if a person did not achieve mastery in each stage then they felt a sense of inadequacy (Cherry, n. d.). People with autism have trouble achieving mastery in each stage, especially in early development when it is most crucial to further development of social interest.

Erikson’s entire stages focus on social engagement. As persons with autism reach the adolescent years, Erikson says they will be successful if they have been encouraged and able to
gain independence (Cherry, n. d.). People with autism typically are challenged to understand that others have different perspectives from them. Therefore, it is entirely possible that they may not perceive that they have been encouraged. They would be missing this crucial step in the stages of development. People with autism often speak negatively about themselves and their capabilities. This may be a result of not having that sense of encouragement as a young child. However, this does not mean the adults in the child’s life were not encouraging. As related to independence, families and schools often over supervise and protect persons with challenges more than their typical peers. Gaining independence is hindered for these persons with autism. Teaching the appropriate skills is needed as well as encouraging increased awareness and acceptance of self.

Armstrong (2007) also talked about the social aspect of development in various stages. He emphasized the importance of relationships, usually starting with the mother. These relationships then grow to include family and friends. As people progress through life, they are faced with many challenges to overcome. Adolescence seems to be a very challenging time. Armstrong pointed out that adolescence seems to creep up on people and take them by surprise. For persons with autism, who have had trouble with social relationships throughout their life, they are now completely blind-sided by adolescence. Adler described development as a time of movement. Armstrong points out adolescents need help to move into adulthood. This is no different for those who have autism. The goal is to help them become independent contributing members of society. Therapists can help them to achieve their goals by encouraging awareness and acceptance so the person will be able to advocate effectively.

Adlerian therapy believes that people can become whatever they want to be (Corey, 2009). Gathering early recollections can be a great way to help gain information and insight about the client’s mistaken thoughts. Early recollections give a glimpse into the way a client
wants or perceives that their life should be. It is then that the therapist can help the client to work toward their goal.

**ASD and Psychotherapy**

When a person with autism is struggling they may decide to seek support and encouragement from a therapist. It is important for therapists working with someone who has autism to understand the types of psychotherapy that are most effective. Of the types of therapy some of the few that seem to work effectively include Individual Psychology (Adlerian), Skills groups, Psychoeducational therapy, Reality Therapy, Cognitive Behavioral Therapy (CBT), Problem-Solving Treatment, and Solution-Focused Therapy. Talk therapy and Biofeedback have also shown some success, but will not be discussed in his paper.

**Skills Groups**

Skills groups are intended to teach ways to improve an individual’s ability to interact socially and appropriately. Playing games is one intervention used in skills groups. Many individuals with autism have a lot of anxiety and this can be particularly challenging for the therapist when you are first trying to get to know a client and introduce a new skill. By playing games with the individual it can actually help to ease some of the anxiety they may be feeling. This is especially true with a game that is easy, or does not require a lot of thought or strategy, but holds the persons attention. Playing games also allows clients to learn a social skill that they can hopefully use with peers. Individuals with autism have many social challenges and are often unsure how to play with and interact with peers. When they have an understanding of how to play popular games and activities, they are likely to have more successful social opportunities and feel as though they belong.

Stress management and relaxation may be used to relieve anxiety with the hope that the client will become more self aware of things that make them anxious, as well as tools to use
when stressed or anxious. Teaching clients to meditate or do some yoga poses can help them to relax and hopefully get back to the task they need to be focused on. For others, stress reduction may occur when they exercise, read, draw, or simply talk about a topic of interest.

Visual aids should be used often when teaching skills. Visual aids such as social stories, power cards and comic strip conversations work well to help people with autism understand the perspectives of others, warn of change and create social awareness. All of these will help to improve the social interest of the client. Video modeling is another visual that is effective in teaching new skills and perspectives of situations. By videotaping the appropriate behaviors and responses, especially today with all the technology, clients are able to see the changes that need to be made and can watch themselves doing it.

Clients with autism thrive when there is structure and predictability. Having clear steps will increase the chances that the client will be able to move toward their goal. Approaches that are also focused and can be accomplished in a short time period are preferred, since many clients with autism also have attention challenges and lose interest in what others are saying. Often times clients with autism have special interests and favorite topics that they often think of, so there may only be a short window of time to problem solve with them and come up with a solution.

**Psychoeducational**

The main interventions in the psychoeducational approach include educating others, skill development and training and relationship development. “Psychoeducational family therapy is now seen as a mandatory component (along with psychopharmacology) in the treatment of major psychoses,” Goldenberg & Goldenberg (2008) quoted this statement from Steinglass (1996, p. 1). Families benefit from gaining knowledge of autism and how it affects their child. They also benefit from learning how to help the person with autism and in building a positive relationship.
Individuals learn about themselves and how their autism can be a strength and a challenge. Such awareness helps to improve their ability to advocate for their unique needs.

Building relationships is a key intervention within the psychoeducational approach. People with autism struggle to build and maintain relationships with others due to their limited interests, inability to read the cues around them and understand the importance of a relationship. It is important for families to understand the individual and build a positive relationship with them. In some families, it is important for extended family members to also build a positive relationship and understanding of the individual with autism, as well as mental health professionals.

**Reality Therapy**

Reality therapy was developed by William Glassor, basically asserting that everyone is a self-determining being (Corey, 2009). All behavior is aimed at satisfying the needs for survival, love and belonging, power, freedom and fun. Behavior is a person’s attempt to control their perceptions of the external world so they fit their internal and need-satisfying world. Reality therapy believes that behavior consists of four components: acting, thinking, feelings, and the physiology that accompanies all a person’s actions. Reality therapy believes that no matter how tough the circumstances are, people always have a choice. Reality therapy does not focus on the medical model of psychoanalytic therapy or the key concepts that focus on the past, dream exploration, dwelling on feelings/insights, transference and the unconscious (Corey, 2009). Rather, Reality therapy believes that each individual is born with five genetically encoded needs: survival, love and belonging, power/achievement, freedom/independence and fun. Much like Adlerian Therapy, Reality therapy believes these needs drive our life and vary in strength. Reality Therapy is effective in helping individuals with autism to see their strengths and make life choices accordingly.
Cognitive Behavioral Therapy

Cognitive Behavioral Therapy (CBT) believes that psychological problems are a result of commonplace processes such as faulty thinking, making incorrect inferences on the basis of incorrect information and failing to distinguish between fantasy and reality. By definition, CBT “teaches people to monitor their own thoughts and perceptions with the hope that they will become more aware of their interpretive errors” (Gaus, 2007, p. 65). Since individuals with autism lack theory of mind and are often unable to recognize and understand the perspectives of others, CBT can help them gain self awareness and therefore be more equipped to advocate for themselves effectively in all areas of their lives.

Problem-Solving Treatment

Problem-solving treatment is a form of CBT and is appropriate for adults and children (AreAn, 2002 and Chang, D’Zurilla & Sanna, 2004). The problem-solving approach is about addressing feelings, thoughts and behaviors, looking at mistakes, and encouraging movement through motivation through a series of concrete steps. Individuals with autism have a difficult time recognizing and understanding the feelings, thoughts and behaviors of others. Most people with autism need help to understand feelings, thoughts and behaviors of others and when they don’t understand and recognize the feelings; problems often arise due to their mistaken understanding. The problem-solving approach helps clients to better understand what they have mistaken and come up with a solution.

The problem-solving approach gives clear structure for the therapist and the client. Individuals with autism thrive when there is structure and predictability. Having clear steps increases the chances that the client will better be able to move toward their goal. Problem-solving approaches are focused and can be accomplished in a short time period which is beneficial since many clients with autism also have attention challenges and loose interest in
what others are saying (Chang, D’Zurilla & Sanna, 2004). As stated previously, clients with autism have special interests and favorite topics that they often think of, so there may only be a short window of time to problem solve with them and come up with a solution.

**Solution-Focused Therapy**

Solution focused therapy helps the individual to find sustainable solutions by focusing on the strengths, competencies and personal qualities rather than focusing on the individuals problems. Solution focused therapy helps the client explore how they can overcome challenges and learn to manage their lives (Bliss & Edmonds, 2008). Much like Adlerian therapy, solution focused therapists take time to listen to what the client is saying, but not to pass judgment and make assumptions about them. In solution focused therapy, the therapist is confident in believing that the client knows what is best for them and simply helps them to see the positive skills and strengths they already have (Bliss & Edmonds, 2008).

Similar to Adlerian therapy the solution focused therapist may use a ‘miracle question’ to help the client to see the situation not just the problem and think about a solution (Bliss & Edmonds, 2008). Individuals with autism tend to take in information and perceive situations differently than the neurotypical person, so by asking a ‘miracle question’ it can help the therapist know where the person is striving to be and possibly understand their goals.

Solution focused therapy can help the client with autism to think about their strengths and learn ways to foster this in a positive way. Bliss and Edmonds (2008) believe that Solution Focused therapy fits well with individuals with autism because it allows the therapist to work with the strengths, challenges and goals of the individual in a way that makes sense to an individual who has difficulties in such areas as information processing, cognitive, sensory and perceptual reasoning. Solution focused therapy improves a person’s self awareness and
acceptance, therefore giving them the tools needed to advocate for themselves confidently in all areas of their lives.

**Conclusion**

As the number of people affected with autism continues to increase, so does the need for support and understanding from therapists to help them. Since individuals with autism are significantly impacted, especially with their social interactions and awareness, it is important that those who work with them have an understanding of autism and how to help each of them gain independence and a sense of belonging in their community. It is important to help individuals to reach their true potential in life and in themselves. Having self awareness is the first step toward a person with autism to accept who they truly are. Once they have accepted who they are, it will be easier for them to learn to advocate for themselves. If they are not able to advocate for themselves, they are more dependent on others and less likely to achieve their independent potential.

Family is key to helping the individual to accept themselves and be able to self-advocate effectively. Without the support of family, including siblings, the person will continue to be dependent on the help of others rather than being able to get their own needs met and gain a sense of belonging, safety and security.

Adler’s focus on social interest and the belief that all individuals have social interest fits well with clients with autism. All individuals with autism want to belong. They have social interest, but may not show it or perceive it in the same way as someone without autism. With the encouragement and guidance of a therapist, a person with autism is capable of belonging within their family and community. Once they accept who they are, it is then that they will be able to advocate for themselves. Therapists and family members can help the person to make changes
that lead them in a positive direction toward their goal while also being a positive member of society.
References


Presentation Process Paper

Methodology

Design of the Presentation

The ideas for this presentation were developed during the course of our current roles as Autism Specialists in local school districts as well as our coursework at Adler Graduate School. Through our work with Sheila Merzer MA, LP at our internship, we began to see more trends in the area of self-advocacy. In our work with young people with Autism Spectrum Disorders, we repeatedly are faced with individuals who prefer to isolate rather than join in their communities. In using what we have learned about Adlerian Psychology and the need to belong we began to formulate a presentation addressing the Autism Spectrum Disorders needs as well as the need to belong.

Population

This presentation is designed for those working with individuals with Autism Spectrum Disorders (parents, educators, mental health professionals, etc.).

Presentation Development

The development of this presentation began when we were approached by a school district to present training on self-advocacy skills to a group of educators. We began to research this topic and started to see reoccurring themes of belonging and social interest, which led us to make the connection to Adlerian Psychology. As a result we wanted to develop training for mental health professionals, parents, and educators.

We submitted a proposal to AuSM (Autism Society of MN) and were chosen to present at the State of Minnesota Autism Conference in April of 2012. We created a power point presentation and handouts for the conference. We videotaped the presentation given on April 27, 2012 for a group of 75 attendees.
Description of Presentation

Advocate and Succeed (Taken from the AuSM state conference program, 2012)

It’s hard for anyone to advocate for themselves, but when you struggle with basic social skills, it becomes impossible to navigate alone. So come and learn the power to reaching self-advocacy to individuals on the spectrum. This breakout will address the skills necessary for effective self-advocacy and the strategies for teaching these skills. Understanding the importance of social connection opens up doors to leading a successful life for individual with ASD.

Summary of Project

Personal Reflections

We are very pleased with the outcome of the presentation. The breakout session was well attended. We received positive feedback and comments at the conclusion of the presentation. We are happy with the pacing of the presentation and our ability to remain within our time limit. We feel we were able to balance out the speaking parts of the presentation evenly between us. We are excited to hear the positive comments and the opportunity to continue to make connections with families, educators and other professionals who attended our presentation.

Evaluations

Participants completed a general evaluation for the entire conference. A blank copy of the evaluation is included in this paper. Results will not be released from AuSM until later in June or early July. We have had people contact us for further help since giving the presentation in April. We also have heard positive feedback from others that attended.

Participants asked questions during and after the presentation. Questions they asked were related to the use of visual supports, the individual’s acceptance of their diagnosis and how to disclose about their disability. The questions helped participants to further their understanding
and knowledge of individuals with ASD and how to support them through their journey of becoming a self advocate.

**Future Plans**

We plan on expanding the concepts in our presentation into a book format in the future. We would also like to develop and present workshops related to bullying and how not to become the victim.

**Conclusion**

It is our hope that through this presentation a greater awareness and understanding of Autism Spectrum Disorders and the need for self-advocacy skills has occurred so individuals can gain a sense of belonging and become productive members of their communities and be socially accepted.
Appendix A

Call for Papers - Proposal Submission Form

2012 Minnesota Autism Conference
Minneapolis, MN
Sessions April 27th & 28th, 2012

FIRM DEADLINE FOR ALL PROPOSAL SUBMISSIONS – January 15th, 2012

Instructions

Proposal submissions for the 17th Annual Minnesota Autism Conference in Minneapolis, MN are accepted in MSWord format only using this form. Please download/save this form to your computer, then save it as a new file, using the last and first names of the contact person. If submitting more than one proposal under the same contact person’s name, please add a number at the end of the file name to distinguish multiple proposals. Example: If contact person is John Smith, filename should be smithjohn1.doc; second proposal should be named smithjohn2.doc. etc. To enter required information in the Word document, click on the gray boxes below and type in your text. For check boxes, click to highlight box and then type an “x.” Don’t forget to save your work. Only one proposal will be chosen.

Please send only one (1) email that includes the completed proposal (all items, A through U) as an attachment to Janette Johnson at jjohnson@ausm.org.

A. Title of Presentation

12 words maximum.

Self-advocacy skills for individuals with Autism Spectrum Disorders

B. Abstract

50 words maximum, appropriate for inclusion in the conference program.

When working with individuals with ASD it is important to consider his or her ability to communicate and thus effectively advocate. In an educational or therapeutic setting it is critical to teach the skills necessary to advocate in order to communicate effectively, fit into social groups, and find a sense of belonging in their communities. This workshop will address skills necessary for self-advocacy and strategies for teaching these skills.

C. Learner Objectives

Include one or more learner objectives to be addressed through this presentation.

- Participants will learn
- How to identify skills necessary for effective self-advocacy
- Strategies for teaching self-advocacy skills
- Importance of social connections

D. Description

Please provide sufficient information concerning the proposal for reviewers to evaluate its suitability for this year’s conference. Please do not simply include an outline, but rather write in narrative form. Clinical proposals should include information on assessment and documentation. (300 word maximum)

By understanding the social challenges individuals with ASD experience, professionals and parents are better able to teach the skills necessary for effective self-advocacy. This workshop will address skills necessary for self-advocacy and strategies for teaching these skills. Participants will learn how to identify skills necessary for effective self-advocacy, strategies for teaching self-advocacy skills, and the importance of social connections for effective self-advocacy.

2380 Wycliff Street, Suite 102 • St. Paul, MN 55114
Telephone: 651-647-1083 • Fax: 651-647-1220 • Website: www.ausm.org • Email: info@ausm.org
### E. Bibliography

Please list 5-10 references which are relevant to the content of the presentation.


### F. Target Audience

Check one or as many of the audience groups for whom you feel this session is appropriate.

- [ ] Educators - Beginner
- [x] Educators - Advanced
- [ ] Families/Parents - Level 1 - Newly Diagnosed
- [x] Families/Parents - Level 2 - Middle School
- [x] Families/Parents - Level 3 - Young Adult/Employment

### G. Key Words

List one or more key words that denote the main topic(s) of the presentation.

- Autism Spectrum Disorders and Self-Advocacy

### H. Presenter Name(s) and Affiliation(s)

Please list your credentials as you would like them to appear in the program. Professional vitae (submit as a separate file in MSWord format) is required for Continuing Music Therapy Education (CMTE) course consideration. Presenters' names will be listed in alphabetical order in the conference programs.

- Kim Busse, M.A. Autism Specialist
- Amy Reid, M.Ed. Autism Specialist

### I. Contact Information

Please list the name, address, telephone, fax and e-mail of the contact person for this session. The contact person's information will be used as the sole contact by the conference planners. The contact person is responsible for communicating all information with all other presenters as necessary.

Kim Busse & Amy Reid 13600 Princeton Circle Savage, MN 55378 612-328-4248
bussereid@gmail.com

### J. Mini-Biography

Provide a very short biography of each presenter. (30 word maximum per person)

- **Kim Busse:**
  - Kim is an Autism Specialist with Edina Schools and a graduate student at Adler Graduate School. She has been working with individuals with Autism for over ten years.

- **Amy Reid:**
  - Amy is an Autism Specialist with the Burnsville Transition Program and is a graduate student at Adler Graduate School. She has been working with individuals with Autism for over ten years.
### K. Past Presentations

List 1-3 recent related presentations/publications by presenter(s).

- MRVSEC – August 2011
- Learning Curve parent group - August 2011
- AUSM - 2008
- NACMH 2008

### L. Format

- Panel/Symposium
- Roundtable
- Workshop

### M. Special Workshop

Would you like to have this presentation considered for an AUSM workshop to be scheduled before or after the conference?

- Yes — If yes, please list any prerequisites:
- No

Please list your first and second choices for the preferred length for this special course. Please provide an estimate only; times may need to be adjusted due to scheduling needs.

- One hour
- 1.5 hours
- 2 hours
- 4.5 hours

### O. AV Requirements

AUSM will supply a standard package of AV equipment for each session room. Accepted presentations will be required to utilize only the equipment in the package (podium & LCD). AUSM will make every effort to accommodate requests outside of the standard package and will assess fees as they apply. AUSM is unable to provide computers, video equipment or software.

I agree to the AV policy: ☐ Yes ☑ No

Additional comments: Ability to run audio through our computer to show video with sound

### S. Recording

Are you willing to have your session audio or video recorded? (The contact person should answer on behalf of a group of presenters for a joint proposal. Please check with all presenters before answering.)

- This presentation may be audio recorded: ☑ Yes ☐ No
- This presentation may be video recorded: ☐ Yes ☑ No

### U. Contract

By submitting this proposal electronically, it is understood that I have affixed my signature and agree to abide by all policies and regulations as outlined above. I agree to present at any time during the conference at which my presentation is scheduled. I understand that not presenting at the agreed time and date may result in my not being invited to present at future conferences.

- I Agree ☑ No Disagree ☐

Electronic Signature (full name): Amy M. Reid

Date signed: 01/08/2012

---

2380 Wycliff Street, Suite 102 • St. Paul, MN 55114

Telephone: 651-647-1083 • Fax: 651-642-1230 • Website: www.ausm.org • Email: info@ausm.org
You will be notified in February 2012 as to the status of your proposal.

Thank you for your commitment to participate in the Minnesota Autism Conference. Your experience, expertise and willingness to share with others are what make our conference a success.
Appendix B

Presentation Agreement
2012 Minnesota Autism Conference

Event Details
April 25-28th
Doubletree Hotel Minneapolis Park Place
1500 Park Place Blvd.
Minneapolis, MN 55416

Today's Date: February 28, 2012

The Autism Society of Minnesota requests Kim Busse and Amy Reid to make a 60 minute presentation on Self-Advocacy Skills for Individuals with Autism Spectrum Disorder on the date of April 27th from 11 am - Noon.

Audio Visual Requirements
One microphone, a podium, LCD projector and white screen will be provided. If you have additional AV needs, please contact us. We will do our best to accommodate your request. However, this request may result in an extra cost. Please note that if you will be using a Mac laptop, you will need to have an adapter to connect to the LCD projector.

Presentation Materials Requirements
A copy of your presentation materials is due to AuSM by April 1, 2012. Due to the rise in printing costs, please consider providing your own printed set of handouts as a donation.

☒ Yes, I will be providing 125 handouts for my presentation.

☐ No, AuSM will provide the handouts. Presentations must be formatted as a PDF with 3 slides per page and emailed to events@ausm.org by April 1, 2012.

A signed contract must be returned via fax, attn: Luann Quayle at 651-642-1230 by March 5th, 2012.

I agree to make a presentation for the Autism Society of Minnesota on the above date and time. I have read and understand the audio/visual requirements and the presentation material requirements. I understand there is no financial compensation for this presentation, or any expenses that may be incurred.

Kim Busse  
Speaker Name Printed  
2/28/12  
Date

Amy Reid  
Signature  
2/28/12  
Date
**Appendix C**

**Break out Speaker info**

Luann Quayle <lquayle.ausm@gmail.com>  
To: anab a guiaid <anabguigail@gmail.com>, "Stansberry-Brusnahan, Laroye L." <lists@stthomas.edu>, Todd schwartzberg <toddsmtbc@aol.com>, "Jason J. Backes" <jbackes@district287.org>, Caryn Sullivan <carynsullivanscribe@gmail.com>, Mary Olson <olsonriverbank.k12.mn.us>, kaynez411@hotmail.com, "Sievers, Phil (MDE)" <phil.sievers@state.mn.us>, barb kavan <barb@trainmanandmom.com>, michelle@kidsconsulting.org, "dilley, erin" <erin.dilley@austin.k12.mn.us>, danner7@usfamily.net, "Meg Williams, MA, LAMFT" <meg.wilms@gmail.com>, julie@upstreamarts.org, kathywilmes@frontiernet.net, "Steblay, Maura" <msteblay@financialguide.com>, James Rechs <jamesrechs@yahoo.com>, bussereid@gmail.com, lptalvitie@gmail.com, timm0112@umn.edu, kaynez411@hotmail.com

Hello everyone,

I am hoping this finds all of you well—in good health and good spirits. In the middle of this very busy time before the conference, I wanted to connect with you.

* I have been receiving handouts from many of you. If you would like AuSM to print the handout for your breakout session, please send me the pdf of your presentation by Thursday, April 12th. If you are printing your own, please arrive with 125 copies on the day of your presentation.

* You are welcome to attend the conference at no charge on the day of your presentation, and join us for lunch. If you wish to attend any other days, you will need to register and pay for those days on your own.

* If you have any AV needs other than what are detailed in the breakout contract, please let me know ASAP. Most of you have done this already, but sometimes things change.

Thank you so much for being a part of the 17th Annual AuSM Conference!

---

Luann Quayle  
Education Specialist  
651-647-1083 ext. 22  
Autism Society of Minnesota (AuSM)  
lquayle.ausm@gmail.com | www.ausm.org

https://mail.google.com/mail/?ui=2&ik=9778be554e&view=pt&search=inbox&th=1369de6d403b2aa1
Additional Breakout Speaker Info

Luann Quayle  <lquayle.ausm@gmail.com>
To: Luann Quayle  <lquayle.ausm@gmail.com>
Bcc: busserid@gmail.com

Greetings,

Before you know it, it will be April 25th and the 17th Annual AuSM State Conference will be off and running! This message is just to clarify a few more details regarding your breakout sessions. If anything isn't clear or you still need help, please send me an email and we'll try to get an answer for you as quickly as possible.

*All sessions take place at the Double Tree Park Place Hotel, 1500 Park Place Blvd, Minneapolis 55416. When you arrive at the hotel on the day of your presentation, come to the Registration area on the Second floor. At the smaller Registration table, you will receive a conference packet and a speaker nametag.

*The Friday sessions take place at 11 am, 1 pm and 2:30 pm, and Saturday sessions at 10 am and 11:15 am. You will be able to get into your respective rooms approximately 20 minutes beforehand to set up for your session. Both Janette and I will be circulating between rooms to ensure that you all have the proper AV equipment and everything is in working order. If you have multiple presenters, there will be a microphone for each of you. I am attaching a copy of the program so you may check your time and room location.

*There will be a volunteer to do an introduction for you, and they can reach us if anything unexpected happens.

*If AuSM is printing your handouts, they will be waiting in your assigned room and the volunteer will be in charge of distributing them.

*Please join us for lunch the day of your presentation, and let us know if you have any special dietary needs.

If you need to reach me, my cell number is 651-325-5398.

Luann Quayle
Education Specialist
651-647-1083 ext. 22
Autism Society of Minnesota (AuSM)
lquayle.ausm@gmail.com | www.ausm.org

2012 Conference Program.pdf
4342K
Session I: 11:00 am to 12:00 pm

**Somali Culture and Autism**

It is vital for educators and professionals to understand how culture impacts the families they serve. Cultures vary as the autism spectrum itself varies. Through this session you will gain an understanding of how Somalis view normal development and disability. This understanding will enhance your ability to reach and treat this group of families living with autism. Come and learn how to provide services and resources in a culturally and linguistically appropriate way.

**Anab Adan Gulaid, BASc, MPA,** has proven knowledge of working with diverse populations, as well as extensive knowledge of health education and health communication principles, techniques and strategies. Anab is working as a Autism Surveillance Project facilitator and as a consultant for the Environmental Health Section of the Saint Paul-Ramsey County Public Health Department. She is the founder and executive director of Eftin, a nonprofit organization, and previous chair of Somali Health Coalition of MN.

**Abdul Diriya** parents two children with autism.

**Advocate and Succeed**

It’s hard for anyone to advocate for themselves, but when you struggle with basic social skills, it becomes impossible to navigate alone. So come and learn the power to teaching self-advocacy to individuals on the spectrum. This breakout will address the skills necessary for effective self-advocacy and the strategies for teaching these skills. Understanding the importance of social connection opens up doors to leading a successful life for individuals with ASD.

**Kim Busse MA,** is an autism specialist with Edina schools and a graduate student at Adler. She has been working with individuals with autism for over ten years.

**Amy Reid, MED,** is an autism specialist with the Burnsville Transition Program and is a graduate student at Adler. She has been working with individuals with autism for over ten years.
17th Annual Minnesota Autism Conference
Evaluation Form
April 25 – 28, 2012

Thank you for participating in the conference. We would appreciate it if you could please take a minute to complete the evaluation. This will help us determine what you liked and what we can improve on for future conferences.

1. Was the AuSM Annual Conference, “Scaling the Summit” helpful or useful to you?

2. What did you like about the conference?

3. Do you feel what was presented was helpful for you?

4. Were the presenter[s] knowledgeable and effective?

5. What would you change?

6. What is your role in the Autism Community?

7. Are there other topics you would like to see the Autism Society of Minnesota present?

RATE QUALITY:  HIGH   AVERAGE   LOW

10  9  8  7  6  5  4  3  2  1

COMMENTS:

THANK YOU!

2380 Wycliff Street, Suite 102 • St. Paul, MN 55114
Telephone: 651-647-1083 • Fax: 651-642-1230 • Website: www.ausm.org • Email: info@ausm.org
Appendix E

Karen Felling <karencajfelling@juno.com>
Re: questions
February 28, 2012 8:39 PM

Yikes, sorry I am just getting back to you. This got buried in my in box. I work on this with my clients by helping them to realize what is likely to trigger difficult moments for them, such as feeling anger, depression, anxiety, loneliness, etc. Without being able to recognize personal triggers most of my clients aren’t able to advocate for themselves because they aren’t able to recognize what they need. Some of my clients are working on initiation, particularly with authority figures, such as teachers. With those kids we work on voice tone and how to state needs without presenting as critical of another person. Other clients are working on self-esteem issues such as learning to disagree with friends or initiate with friends. I have teens who I assign homework assignments such as being the one to suggest what they do when the group is hanging out.

I don’t have specific resources I recommend to clients. For my really introverted clients doing a Myers Briggs can be helpful to shift their understanding of introversion.

Hopefully this helps!

You will have to have a big party when you finish!

Karen

Sent from my iPad

On Feb 21, 2012, at 8:42 PM, Amy Reid <amymreid@yahoo.com> wrote:

Hello,

Kim Busse and I are working on our master’s project. Our topic is self-advocacy and ASD. We are collecting information on how self-advocacy skills are addressed in a therapeutic environment. If you could provide us with some information/thoughts on the following questions it would be much appreciated:

How do you address the development of self-advocacy skills in the therapeutic setting?
What resources do you recommend to address self-advocacy?

Thank you so much for your assistance with our master’s project!

Amy M. Reid
amymreid@yahoo.com

53 Year Old Mom Looks 33
The Stunning Results Of Her Wrinkle Trick Has Botox Doctors Worried
cosmeticprocedures.com
Kim Busse  
Autism Specialist  
Edina Public Schools  
Office 952.848.3076  
Cell 612.219.8633

From: dawn bove' [dbove.lp@gmail.com]  
Sent: Monday, February 27, 2012 3:33 PM  
To: Busse, Kimberly K  
Subject: Re: questions

On Fri, Feb 24, 2012 at 1:15 PM, Busse, Kimberly K <kimbusse@edina.k12.mn.us> wrote:  
Great. Thanks  
Kim

Sent from my iPad Kim Busse

On Feb 24, 2012, at 1:04 PM, "dawn bove" <dbove.lp@gmail.com> wrote:  
Hi Kim- I'll respond over the weekend as I'd like to give this a little thought before sending it to you. thanks, dawn

On Thu, Feb 23, 2012 at 11:31 AM, Busse, Kimberly K <kimbusse@edina.k12.mn.us> wrote:  
Hello,  
Amy Reid and I are working on our master's project. Our topic is self-advocacy and ASD. We are collecting information on how self-advocacy skills are addressed in a therapeutic environment. If you could provide us with some information/thoughts on the following questions it would be much appreciated:

How do you address the development of self-advocacy skills in the therapeutic setting?  
What resources do you recommend to address self-advocacy?  
https://mail.google.com/mail/u/2?ui=2&ik=9776be55a6&view=pt&search=all&safe=0&rsn=0&rsn=0&cid=CE4DB50C3680C2122&attid=0.1&lib=2&store=mx&attview方式性 Pere
Self Advocacy- one of the first things is helping the client figure out when they need help, and who to go to if they do. I sometimes have a client make a list of who to ask for help with specific kinds of problems. It's important to get past the clients reluctance to even ask for help. It helps if you can tie this skill to something that's of interest or motivating for the client. I work on this on a case by case basis and then try to help the client (those who may work with them as well) generalize this skill (ie what could you do when you are going to miss the first day of class because of a family commitment, who can you call, etc.) More recently I've been including information from an ASD and college handbook that identifies the skills that one with ASD should/needs to have, in order to be successful as a general guide and as a way to identify individual client tx. goals.

hope this is helpful kim-It would be good to hear what your findings are once you've completed your project.

dawn

Thank you so much for your assistance with our master's project!

Kim Busse
Autism Specialist
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Cell 612-219-8633
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Website: https://sites.google.com/site/edinaasad/

https://mail.google.com/mail/?ui=2&ik=9776be55aa&view=pt&ct=Adler620Master%20Sc20Project&search=cat&th=135c0e13ec2aa21222b8
Self-Advocacy for Individuals with Autism Spectrum Disorders

2012 Minnesota Autism Conference
April 27, 2012

Presented By:
Kim Busse
Amy Reid

Goals for this workshop:
- Understanding of impaired social interactions
- Understanding of Theory of Mind
- Skills necessary for effective self-advocacy
- Importance of social connections
- Strategies for self-advocacy
The Arc’s position on self-advocacy states that “self-advocacy means acting and communicating for oneself”.

Self-advocacy groups provide individuals with developmental disabilities their first and most consistent opportunities to develop membership and leadership skills.

“Self advocacy begins by understanding that rights are never granted from above. They are grasped from below by those with the courage and determination to seize that to which they are entitled.”

- Tony Coelho

Individuals can advocate for their wants and needs and belong in their communities.
It can be easy to focus on challenges and limitations but, focusing on abilities and finding ways to advocate lead to success.

SABE: Self Advocates Becoming Empowered (SABE) is the self-advocacy organization of the United States. Founded in 1990, we have been working hard for the full inclusion of people with developmental disabilities in the community throughout the 50 states and the world for 21 years. Our non-profit advocacy organization is run by a board of self-advocates representing 9 regions of the country.

AuSM: The Autism Society of Minnesota (AuSM) is an organization of families, educators, caregivers, and professionals committed to supporting individuals with autism spectrum disorders (ASD). It was established in 1971. AuSM has members throughout the state of Minnesota and the upper Midwest.

Autism Society: The Autism Society, the nation’s leading grassroots autism organization, exists to improve the lives of all affected by autism. We do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

ACT: is a disability rights organization, non-profit, run by and for people with developmental disabilities and other disabilities

MCIL: offers Individual Advocacy and Systems Advocacy. Both types of advocates assist people who have any sort of disability. Individual advocates work one-on-one with consumers, combining their voices and experiences to solve daily problems and navigate the bureaucracy
maze. Systems advocates’ initiate, develop, and implement public policy. They work with government officials, community groups, and private businesses in an effort to improve the lives of people with disabilities.
Even in areas one might think require primarily academic or cognitive skills, such as school or work, having limited social skills can be devastating.

For instance, college is arguably as much about the social experiences as it is about earning a degree.

Dating and romantic relationships can be especially confusing. For example, individuals with Asperger’s have trouble interpreting signs from the opposite sex, meaning it is easy for them to either be taken advantage of or mislabeled as a stalker.

At work, even a good employee can find their job in danger if they “fail coffee break.”

Individuals with Asperger’s are chronically under- and un-employed, due to problems arising from lack of social understanding, such as difficulty with interviewing, failure to respect coworkers’ personal space, talking too much or too little, or inappropriate dress or personal habits.

In individuals with ASD there is already a social impairment so this might be an area where we see more obvious evidence of Executive Functioning deficits or differences.

An individual may be confused by social cues, struggle with reciprocal conversation with peers. These individuals may or may not desire to be social with their peers.
Social coaching – Social coaching focusing and incorporates an Executive Functioning model may significantly improve an individual's ability to learn how to be more confident. Social coaching helps individuals identify personal strengths and challenges (including understanding his or her diagnosis).

Social coaching provided individuals with tools necessary for success in social environments.
Perspective taking---

Michelle Garcia Winner

4 steps of perspective taking:

1. Each person is aware of and has small thoughts about everyone else around him or her.

2. People think about why people are near them...do they want something (motive)

3. People think about what others are thinking about them.

4. People monitor and possibly modify their own behavior based on what they want other people to think.

Social thinking refers to the process of thinking your own thoughts and about the thoughts of others, and figuring out how to make other people think the way you want them to think about you page.

We use social thinking all the time, even when we’re alone. Social thinking is something you do 24/7.
• Tony Attwood defines Theory of Mind as:

  – “From the age of around four years, children understand that other people have thoughts, knowledge, beliefs and desires that will influence their behavior.”

  – “People with Asperger’s Syndrome appear to have some difficulty conceptualizing and appreciating the thoughts and feelings of another person.”

  – “For example, they may not realize that their comment could cause offence or embarrassment or that an apology would help to repair the person’s feelings.”
If you do not understand yourself and your characteristics it is impossible to identify those same characteristics in others.

Invisible nature of ASD

Professionals: Social Workers, Voc. Rehab, Mental Health Professionals, Teachers
Self-Acceptance

- Knowing about their disability help to feel as if they are not crazy
- Knowing helps them to feel they belong to a group of other individuals who are like them
- Knowing helps them to feel proud
- Knowing helps them to understand themselves and move toward greater self acceptance and less self-blame
- Knowing helps advocate for self (strengths and challenges)

Self Advocacy & Disclosure

- An important part of self-advocacy is disclosure.
- Disclosure is telling someone that you have autism or Asperger’s.
- Disclosure can be scary and sometimes it is difficult to know when to tell about a disability.
Functions of Self-disclosure

Self-disclosure performs several functions:
- It is a way of gaining information about another person
- To be able to predict the thoughts and actions of people we know
- Self-disclosure is one way to learn about how another person thinks and feels
- Mutual disclosure deepens trust in the relationships and helps both people understand each other more
- You also come to feel better about yourself and your relationship when the other person accepts what you tell them

Risks of Self-Disclosure

- One risk is that the person will not respond favorably to the information
- Self-disclosure does not automatically lead to favorable impressions
- The other person may gain power in the relationship because of the information they possess
- Too much self-disclosure that comes too early in a relationship can damage the relationship

Share a story about disclosure
What is Self-Advocacy?

“Self-advocacy is related to the ability to determine how we would like to live our life, make life choices that are meaningful, and express likes and dislikes.”

Kirby Lentz Ed.D. Pg. 84

How to advocate...

- Identify when help is needed & then asking for help
- Being able to identify strengths and challenges
- Student led IEP’s
- Know accommodations
- Know who are supportive individuals to go to
- Have knowledge of outside resources
- Researching
- Accepting who they are

How and what to research/information gathering... Autism, Accommodations, Other’s with autism
Share needs and wants (accommodations) either verbally or in written form

Write a letter

Send an email, Make a copy of accommodations on IEP, Ask for a meeting to talk

Where to advocate: college setting, Work place, community
CBT--- Teaches people to monitor their own thoughts and perceptions and become more aware of themselves.

**Solution Focused Therapy**- focuses what the client wants to get out of therapy rather than the problem. This therapy focuses on the present and future and not the past.

**Bio-Feedback**- the process of becoming aware of various physiological functions using instruments to provide information. May be used to improve health and performance and physiological changes occur in conjunction with changes to thoughts, emotions and behaviors.

**Talk Therapy**- Talk therapy is simply talking about what is bothering you. Talk therapy can be practiced with a friend or loved one, a family member, or a therapist.

**Skills Groups**- used to teach ways to improve ability to interact socially.

**Reality Therapy**- considered a CBT approach... focuses on the behaviors or symptom rather than a diagnosis
What we found out through interviewing other clinicians:

Focus on self-awareness, Be able to identify triggers

Without identifying triggers it is difficult to advocate

In the handouts is a resource chart- used to help an individual organize and be able to identify who to communicate with given certain types of problems or situations.
What Alfred Adler called Social interest refers to the idea of the individual as a social being. The way he or she interacts with other people is of extreme importance for psychological health.

Social interest is an inborn capacity of the human being, but it must be fostered during childhood.

Having social interest means feeling like part of a family, a group, a couple, and the human community.

Social interest means to participate, to contribute, to share, to feel accepted, appreciated, and loved as well as accept, appreciate and love other people too.

Social interest is a feeling of belonging to others and not being “outside”. Oberst & Stewart pages 12, 17---19.
Must have success in these areas to meet life’s challenges.

Leak & Leak Social Interest is required for healthy functioning

Eva Driekers—“All humans need to feel a sense of belonging” Mental health improves when individuals feel belonging.

When social interest and belonging are missing an individual struggles with effective advocacy

Advocating is communicating—can be positive or negative or verbal or non-verbal.

These behaviors can be expected or unexpected. (scripting, repetitive behaviors, jumping around the room, stuttering/start and stop verbal thoughts)
Often it is the individual with ASD’s perception that they don’t fit in or belong... it is not a result of caregiver’s not providing an encouraging environment for the individual.

Penny’s Christmas gift to Sheldon Perspec.ve taking

Social Interest & Self-Advocacy

- Without social interest self-advocacy is difficult for individuals with ASD because:
  - Lacking Theory of Mind
  - Ineffective communication skills
  - Isolation
  - Unexpected behaviors
  - Anxiety
  - Limited opportunities
Theory of Mind
Belonging
Knowing yourself

References & Resources
- Speak Up! (Self-Advocacy Worksheet)
References & Resources


RESOURCES FOR FINDING OUT MORE ABOUT SELF-ADVOCACY...

- http://www.self-advocate.org
- http://www.nami.org/youth/selfadvc.htm
- http://www.arcgreatertwincities.org/
- http://www.pacer.org/
- http://www.ausm.org/
- http://selfadvocacyonline.org/index.asp
- http://www.selfadvocacy.org/index.htm
Contact Information

- Kim Busse
  - 612.219.8633
- Amy Reid
  - 612.328.4248
- bussereid@gmail.com

Busse & Reid, Inc
Autism Speaks
Exploring and Providing Connections for Healthy Living
Appendix G
Examples of accommodations for individuals with ASD

- Assistance with time management (prioritize, deal with procrastination)
- Learning self limiting skills for special interest
- Using visual schedules and supports
- Using voice recognition software
- Help with organizing
- Checking for understanding of instructions
- Use of priming to prepare for next activity/task
- Study skills training
- Guidance for working in groups
- Allow sensory breaks
- Social mentors
- Social coaching/skills
- Warn of changes
### My Resources

<table>
<thead>
<tr>
<th>Agency/Title</th>
<th>Individual's Name</th>
<th>What can he/she do for me?</th>
<th>Questions to ask</th>
<th>Contact information</th>
<th>Other</th>
</tr>
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<tbody>
<tr>
<td>Parent or Guardian</td>
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<tr>
<td>County Social Worker or Case Manager</td>
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<tr>
<td>Mental Health Worker/Therapist</td>
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<td>Primary Doctor/Physician</td>
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<td>Dentist</td>
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<td>Psychiatrist</td>
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<td>School Personal /Case Manager</td>
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<td>IEP Case manager</td>
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<tr>
<td>Transportation Example: MNET</td>
<td>Transportation Line</td>
<td>Transportation to medical appointments</td>
<td></td>
<td>1-866-467-1724</td>
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<tr>
<td>Vocational Rehab Services</td>
<td></td>
<td>Employment plan, college, job placement, etc…</td>
<td>Can you help me find a job? Can you help me register for college? What is on my employment plan?</td>
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