



The Hearth Fire Series #84

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AUTISM: Up-to-Date Research, Expanded Knowledge

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AUTISM

In the span of a few decades, change has occurred in our awareness and understanding of autism. The term autism was first used in 1911 by the Swiss psychiatrist Eugen Bleuler. Early studies of the disorder in the 1930's and 1940's included the works of Leo Kanner in the U.S. and Hans Asperger in Austria. It was not until the 1960's, that the term acquired its current behavioral references. (Bjerklie, p. 4)

Definition of Autism: The current definition of autism spectrum disorder, according to the National Institutes of Health, is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. Although autism can be diagnosed at any age, it is described as a “developmental disorder” because symptoms generally appear in the first two years of life. Both autism and autism spectrum disorder (or ASD) are acceptable ways of referring to the condition.



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Neurodiversity describes the idea that people experience and interact with the world around them in many ways, with no one "right" way of thinking, learning, and behaving, and differences are not always deficits. Neurodiversity refers to the diversity of all people and recognizes that we all have strengths and areas needing support and that our differences can be very valuable. It also recognizes that everyone is worthy of belonging and being able to live a fulfilling life with goals that are meaningful to them. Referring to someone as neurodivergent is a way to focus on the positive aspects of their differences and what that can bring to the group. (NIH)

Autism looks different for everyone, and each person with autism has a definite set of strengths and challenges. Some people with autism can speak, while others are non-speaking and communicate in other ways. Some have intellectual challenges, while some do not. Some require significant support in their daily lives, while others need less support and may live independently. (Autism Speaks)

Prevalence of Autism: In 2000, the CDC began to collect national data in the Autism and Developmental Disabilities Monitoring Network. The prevalence of autism at that time was estimated to be 1 in 150 children. By 2010, the number had risen to 1 in 68; by 2016 was 1 in 54, and by 2022, it is estimated to be 1 in 31.

Anybody can be autistic, regardless of sex, age, race or ethnicity. However, research from the CDC says that boys are diagnosed with autism four times more often than girls. According to the DSM-5, autism may look different in girls and boys. Girls may have more subtle presentation of symptoms, often leading to underdiagnosis or misdiagnosis. Diagnosing an adult with autism can be more difficult, as adults often learn to “mask,” or hide, their autism symptoms. (Autism Speaks)

Well-known factors have contributed to increasing prevalence:

- Heightened awareness and media attention have led to greater recognition of signs and symptoms by caregivers, educators, professionals, and individuals themselves.
- Access to screening has allowed earlier and more accurate identification.

- Additional training of providers in these areas has resulted in more specialized diagnostic programs that are able to accurately identify more subtle presentations of autism.
- An increase in acceptance of this diagnosis has resulted in less stigma that may have previously resulted in people not being as likely to share their diagnosis or their child's diagnosis with others.
- Improvements in data collection have resulted in more comprehensive databases.
- The expansion of diagnostic criteria for autism...In 1994, the Diagnostic and Statistical Manual used to diagnosis autism and other disorders, the DSM-4, introduced the concept of pervasive developmental disorders to identify different presentations of autism...In 2013, the DSM-5 combined these previous diagnoses into an overall diagnosis of Autism Spectrum Disorder and added severity levels and other “specifiers” to the definition of autism, which were intended to help clarify the support levels needed and in doing so broadened the criteria further. The 2022 revision of DSM-5 improved the clarity and consistency of the diagnostic criteria, making it easier for clinicians to apply them in a consistent manner and consider cultural and gender differences in the presentation of autism. (Bjerklie, p. 17)

Cause of Autism: Autism has a strong genetic component. Some research estimates that genes account for about 80 percent of the likelihood of autism, and variants in more than 100 genes have been identified as playing a role. “Some of these gene variants are quite common, and it takes a number of them to accumulate beyond a certain threshold to cause autism,” according to Geraldine Dawson, PhD, founding director and professor at Duke University. “Others are rare and spontaneous, and those gene variants present in an autistic child might not be present in their parents.” The genes that lead to an ASD diagnosis are there when a baby is born and at work even before then. Autism starts during the prenatal period. (Klein, p. 13)



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The gene-environment relationship is still an area of ongoing research, and environmental factors are challenging to study because they are difficult to isolate. There are now several environmental factors that are linked to autism based on solid scientific backing: (There is currently not evidence to indicate that any of these factors alone would “cause” autism, but that the interplay of these factors and genetic predispositions combined can result in an increased likelihood of autism.)

- Parental age at conception. Parents older than 40 have been associated with an increased likelihood of having a child with autism.
- Preterm birth. Babies born prematurely have higher rates of autism. Premies born at just 22 to 27 weeks are almost 4 times as likely to be diagnosed with autism than babies born at full term, at 39 to 41 weeks.
- Birth Complications: knots in umbilical cord, placenta tearing away from the uterus, and babies having to spend time in neonatal intensive care unit (NICU).
- Pregnant mother's health: Obesity, diabetes and the breakdown in the normal functioning of the immune system, leading to autoimmune diseases and chronic inflammation can affect fetal brain development, and have been associated with an increased likelihood of

autism. Making certain mothers have adequate levels of important compounds such as folic acid and vitamin D may make them less likely to have a child with autism.

- Air pollution. Exposure to environmental toxins such as smog during pregnancy has been associated with an increased likelihood of having a baby with autism. The theory is that pollution and other toxins increase inflammation in the pregnant woman, which then affects a fetus's brain development.
- Having another child in the family with autism, with a higher risk in twins and as the number of children with autism in the family increase has also been associated with an increased likelihood of autism. This points to the complexity of genetic and environmental factors involved.

Vaccines do not cause autism. Numerous large studies have shown no link between vaccination and autism. (Klein, pp. 14-16)

Characteristics and Traits of Autism: The two primary areas of an autism diagnosis are social communication and interaction, and restricted or repetitive behaviors and interests.

Joint attention is fundamental for both social communication and interaction, playing a vital role in shaping social skills and cognitive development throughout life. Joint attention is the shared focus of two individuals on an object. It is achieved when one individual alerts another to an object by using eye-gazing, pointing, or a verbal cue. Deficits in joint attention are considered the single most distinguishing characteristic of very young children with autism according to the American Academy of Pediatrics. (Pevzner, p. 19)

Some examples of delays with social communication and interaction can include the following: rarely meets your gaze, does not respond to their name, shows few facial expressions, or does not share back-and-forth exchanges of smiles and sounds. Limited language or gestures, like pointing, can also signal a difference. (Pevzner, p. 19)

Restricted or repetitive behaviors or interests can include the following: pushing a toy back and forth repeatedly, spinning, rocking, hand flapping, or focusing intensely on just parts of an object, like the wheels of a toy vehicle. (Pevzner, p. 20)

Sensory interests or aversions, such as hypo-sensitive or hyper-sensitive to loud noises, bright lights, and uncomfortable clothing, fascination with blinking lights or touching objects to their lips, or strong reactions to food textures, are also common. (Pevzner, p. 20)

There may be other traits of autism related to movement, including delays in gross motor or large movement skills such as walking, jumping, skipping; delayed fine motor or small movement skills like buttoning a shirt or drawing a picture; clumsiness and lack of coordination; poor spatial awareness; difficulty with balance and stability; difficulty with motor planning or praxis; decreased eye-hand coordination; and walking habitually up on toes. (APTA)

Assessment of Autism: There is no medical autism test, like a blood test, to diagnose autism. Instead, experienced medical professionals assess a person's developmental history and behavior, interview and observe the person and their family, and use professional screening and diagnostic tools to make a diagnosis. (Autism Speaks)

Early screening for autism can impact access to services and supports, which in turn can influence future outcomes for individuals with autism. The screening tools below are designed to help identify children and adults who might have autism. A positive result on a screening tool is not a diagnosis. A positive screening result should be followed by a thorough assessment by a health care professional.

There are autism screening tools available at specific ages :

- *Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)* for ages 16 to 30 months
- *Social Attention and Communication Surveillance, Revised (SACS-R)* and *SACS-Preschool (SACS-PR) Tools* for ages 12 to 60 months
- *Social Challenges Screening Questionnaire (SCSQ)* for school aged children
- *Autism Spectrum Quotient (AQ) Test* for ages 16+ (Autism Speaks)

The American Academy of Pediatrics recommends all children between 18 and 24 months are screened for autism during routine visits to the pediatrician. For children under age 3, state early intervention programs offer free developmental evaluations. School-age children can receive free assessments through the public school systems. State and school evaluations may not specifically diagnose autism, but can identify the need for services or further assessment.

A person can be diagnosed with autism at any age, but symptoms typically begin before a child turns two even if they were not noticed until looking back at a later age. These early signs can involve a regression of skills, meaning a young child who had been reaching age-appropriate milestones begins to lose those skills. But newer research suggests babies may have had symptoms of autism, or have at least been experiencing the effects, since birth. (Klein, p. 13)

An evaluation is completed by a developmental pediatrician or neuropsychologist. The gold-standard autism assessment combines the play-based *Autism Diagnostic Observation Schedule (ADOS)* with the *Autism Diagnostic Interview-Revised (ADI-R)*, a structured parent interview about the child's developmental history. (Pevzner, pp. 20-23)

There has also been research in recent years on developing and evaluating reliable teleassessment tools to increase access to families who may live far from centers that specialize in autism diagnosis. (Gangi DN, et. al.)

In 2013, the DSM-5 introduced three ASD levels of severity: Level 1 Autism (requiring support). Level 2 Autism (requiring substantial support) and Level 3 Autism (requiring very substantial support). (Autism Speaks). It is important to note that these levels do not indicate overall severity of autism, but rather the amount of support that an individual currently needs in the two primary areas of an autism diagnosis, social communication and interaction, and restricted or repetitive behaviors and interests. These levels can change over time and may be different across these two areas of the diagnosis.

Importance of Early Intervention Services: Early intervention services leads to the most positive outcomes in all areas of functioning, says Sanam Hafees, PsyD, a neuropsychological assessment specialist in New York City. A 2023 study in the journal *Autism* found that children who began services at 18 months showed more than twice the improvement on social-skills tests

than children who started just nine months later, exhibiting major gains in language, social skills, and cognitive development. (Pevzner, p. 19)

Karen Pierce, PhD, a professor of neurosciences at the University of California San Diego, believes that early diagnosis is critical for the different levels of autism because so many neurological pathways are formed before age 3.

“Kids are born with way more connections, called synapses, between neurons that they’re going to end up with as adults. There’s this process called pruning that happens during the first years of life as really good connections are being formed and less useful connections are pruned away, she explains. Studies have shown that autistic children have more brain cells than their neurotypical peers, and thus more connections.”



Image by Pete Linforth (Pixabay)

Pierce believes this is a key to understanding autism:

“It indicates that autistic children’s brains aren’t pruning cells and forming neural pathways as effectively. If children can be diagnosed early, the hope is that therapies can be created to help them develop more effective neurological connections.” (Flores, p. 28)

Early intervention can make a significant difference in the social, behavioral, communicative, and self-help outcomes for people affected by autism. It is recommended parents and practitioners select an intervention that is an evidence-based practice with scientific evidence to support its claims. (TRIAD ASD tips)

One of the most widely used and researched interventions for autism is applied behavior analysis (ABA). ABA is an organized approach that looks at what affects someone’s behavior and ability to learn and uses that information to teach new skills. There are several types of interventions that fall under the category of ABA, but they all use the same basic behavior principles and may include things like visual support and rewards. The goals of interventions based in ABA are to increase positive behaviors, to teach new skills, to decrease undesired behaviors, and to help children generalize these new skills into the home, school, and other settings where they play and interact with other people. (TRIAD ASD tips)

There have been numerous studies examining different formats and intensity of ABA services and have shown significant improvement through many varied models, including home-based, clinic-based, school-based, direct intervention, and parent coaching for various hours per week across these models.

“Some studies have shown that when ABA therapy was used for more than 20 hours a week during the first few years of life (before age four), it produced large gains in development and even reduced the need for special services later in life.” (Cleveland Clinic)

Individualized approaches can take many forms, including combining ABA with other forms of intervention, such as speech therapy, occupational therapy, and physical therapy. Speech-language pathologists (SLPs) are trained in the assessment, treatment, and prevention of communication

disorders. They typically assess and treat difficulties in language understanding and expression and problems with speech, with articulation and fluency. Social communication, communicating with words and gestures, is hard for young children with autism; therefore, speech-language pathologists are often crucial members of the intervention team. Some SLPs also have training and experience in treating feeding disorders. This is very useful for children with autism who may be selective eaters or have difficulty tolerating certain food tastes or textures, which is more common for children with autism when compared to their same-aged peers. (TRIAD ASD tips)

Some people with autism find that using pictures or technology to communicate is more effective than speaking. This technology is called Alternative Augmentative Communication (AAC) and includes sign language, picture exchange communication system (PECS), Ipads, or speech output devices. A SLP can provide training for AAC devices. (Autism Speaks)

Occupational therapists (OTs) typically focus on helping people develop fine motor skills (movements involving the smaller muscles of the arms and hands) such as writing, coloring, and cutting with scissors; process information from their senses; and carry out daily living activities, such as eating, dressing, and grooming. For young children with autism, OTs are often helpful in building their play skills, learning self-care skills, and coping with their sensory processing differences. (TRIAD ASD tips)

Physical therapists (PTs) are trained to treat problems with movement and posture. PTs tend to focus on developing gross motor skills (movements that involve the larger muscles of the arms and legs). PTs can help children with autism who have difficulties with coordination, balance, or motor planning move about their environment and participate in play and recreational activities more effectively. (TRIAD ASD tips)

Research has shown that individuals with autism may have an increased likelihood of associated medical diagnoses, such as seizures, sleep concerns, and gastrointestinal difficulties. So, depending on the individual assessment of these needs by their pediatricians, having specialists in these areas may also be an integral part of a child's team.

Participation in recreational programs has shown extensive benefits for children with autism. It can reduce behavioral and emotional disorders, help develop social skills and build relationships, improve physical and mental health, and help children develop interests. Many different types of therapeutic recreational activities exist today, serving the unique needs of participants:



Image by wal_172619(Pixabay)

- Music therapy, arts and crafts
- Therapeutic yoga, gymnastics, karate; dance or movement therapy
- Aquatic therapy or swimming (American Autism Association)
- Adapted team sports such as All Play Miracle Baseball League, Pop Warner Challenger Football League and TOP Soccer (Autism Speaks), and the American Special Hockey Association (American Autism Association)
- Animal Assisted Interventions: horses, donkey, rabbits, dogs etc. (Time, FLORES 29)

Transitioning to Adulthood: Navigating the transition to adulthood is often the hardest thing about parenting children with autism. It is important to build independent living skills into the education plan early—to work on independent living skills they will need in the adult world to hold down a job, attend college, or live on their own.

Parents should be prepared for the gap in autism adulthood services. A 2024 disability Health Journal paper found that, nationwide, only about 40 to 60 percent of adults with intellectual and developmental disabilities were enrolled in Medicaid waiver programs (which enable that population to live in the community), with autistic adults having the lowest enrollments of all. The problem is that demand far exceeds access.

Students with autism and their advocates should familiarize themselves with the organizations they will be dealing with in adulthood—the Administration on Intellectual and Developmental Disabilities (AIDD) and the Rehabilitation Services Administration (RSA)—in order to set themselves up for successful negotiations after age 22.

Understanding the financial limitations of the disability services systems is important. Families should start saving money from the very beginning. The student with autism should apply for Supplemental Security Income (SSI) and Medicaid as soon as possible. Students can also open an Achieving a Better Life Experience (ABLE) account or create a special-needs trust without losing their SSI or Medicaid benefits. Parents should explore advocacy organizations like Arc of the United States or the Autism Society of America to learn their legal rights and financial regulations. If supported housing is a part of an expected outcome for adulthood, they should consider getting on a waiting list for the Housing Choice Voucher (HCV) program, also known as Section 8, as soon as possible so they can access low-income housing.

College-bound students with autism should know that they may have to advocate for their own accommodations when they leave high school. (Senator, pp. 50-56). However, many colleges have programs for students with autism to provide accommodations and supports, especially if they had an Individualized Education Plan (IEP) in High School. There are also post-secondary programs that focus on providing support for students with autism who may have greater needs while allowing for a meaningful academic and social college experience.

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Mary Alice Weber is a Retired Physical Therapist with 20+ years experience with toddlers and children with autism, former member of the Waves Autism Spectrum Disorders Program. She and her husband also led a local community Top Soccer program for a few years.

Leader Guide

Autism: Up-to-Date Research, Expanded Knowledge

Welcome, Introduction of Speakers, Introduction of Topic 3 minutes

Introduction of Topic: In the span of a few decades, our awareness and understanding of autism has improved. Advances have been made in early diagnosis and expanded interventions. However, there are many things yet to be discovered about autism. This Hearth Fire discusses the prevalence and cause of autism, the characteristics and traits of autism, the assessment of autism including the newest DSM-5 criteria, the importance of early intervention and therapies, and the need for planning and preparation for a gap in services as the student transitions away from school-based services into adulthood.

Introduction of lesson and speakers 1 minute

Definition of autism and neurodiversity 3 minutes

Activity 1: Autism Empowerment Word Search. 3 minutes

Prevalence of autism 2 minutes

Cause of autism 4 minutes

Characteristics and traits of autism 2 minutes

Screening/assessment of autism 3 minutes

Importance of early intervention 2 minutes

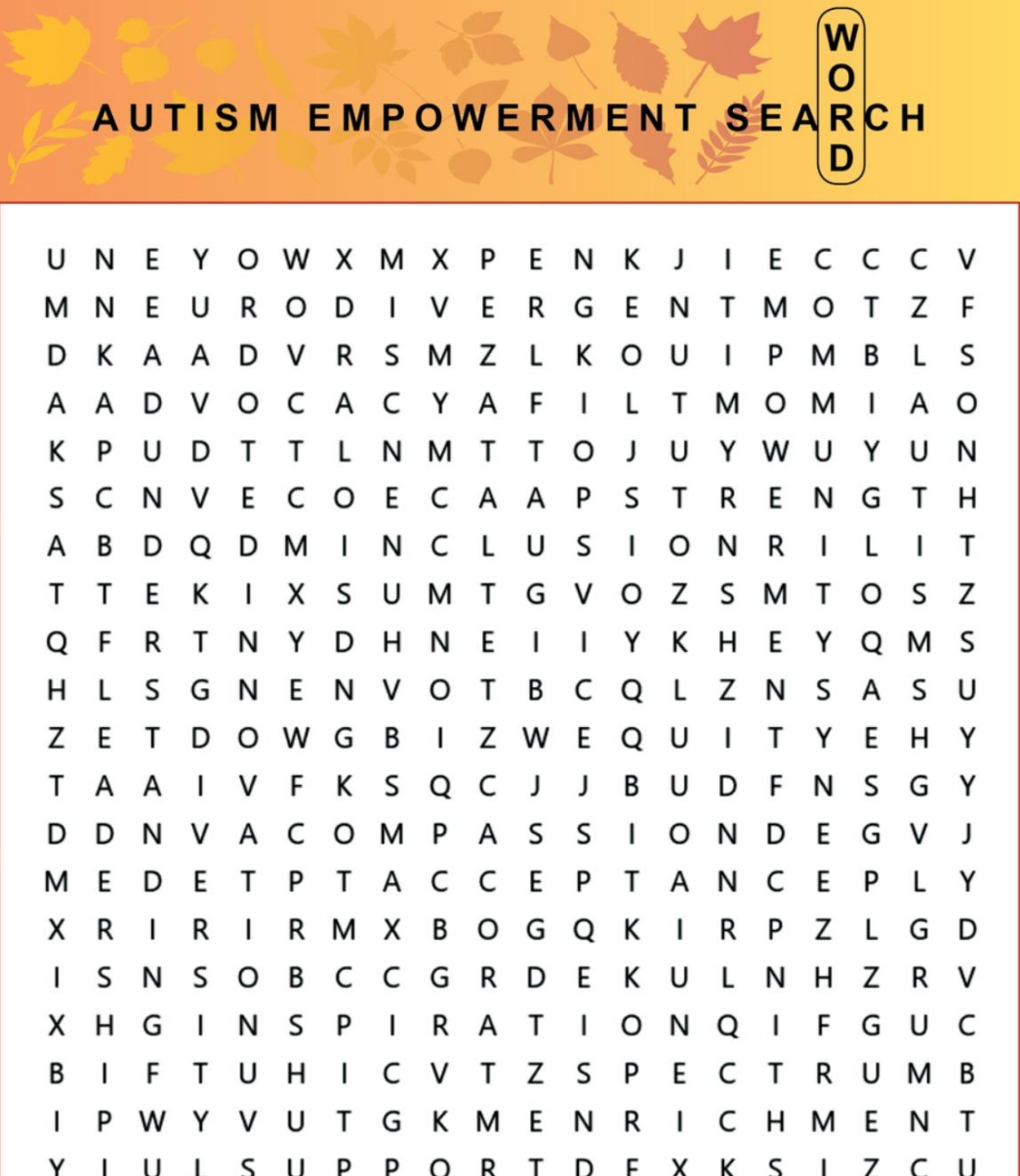
Services for individuals with autism 5 minutes

Transitioning to adulthood—gap in adulthood services 3 minutes

Activity 2: Community Awareness Activity 17 minutes

Closing – Answer any questions/take comments 10 minutes

Activity 1: Autism Word Search



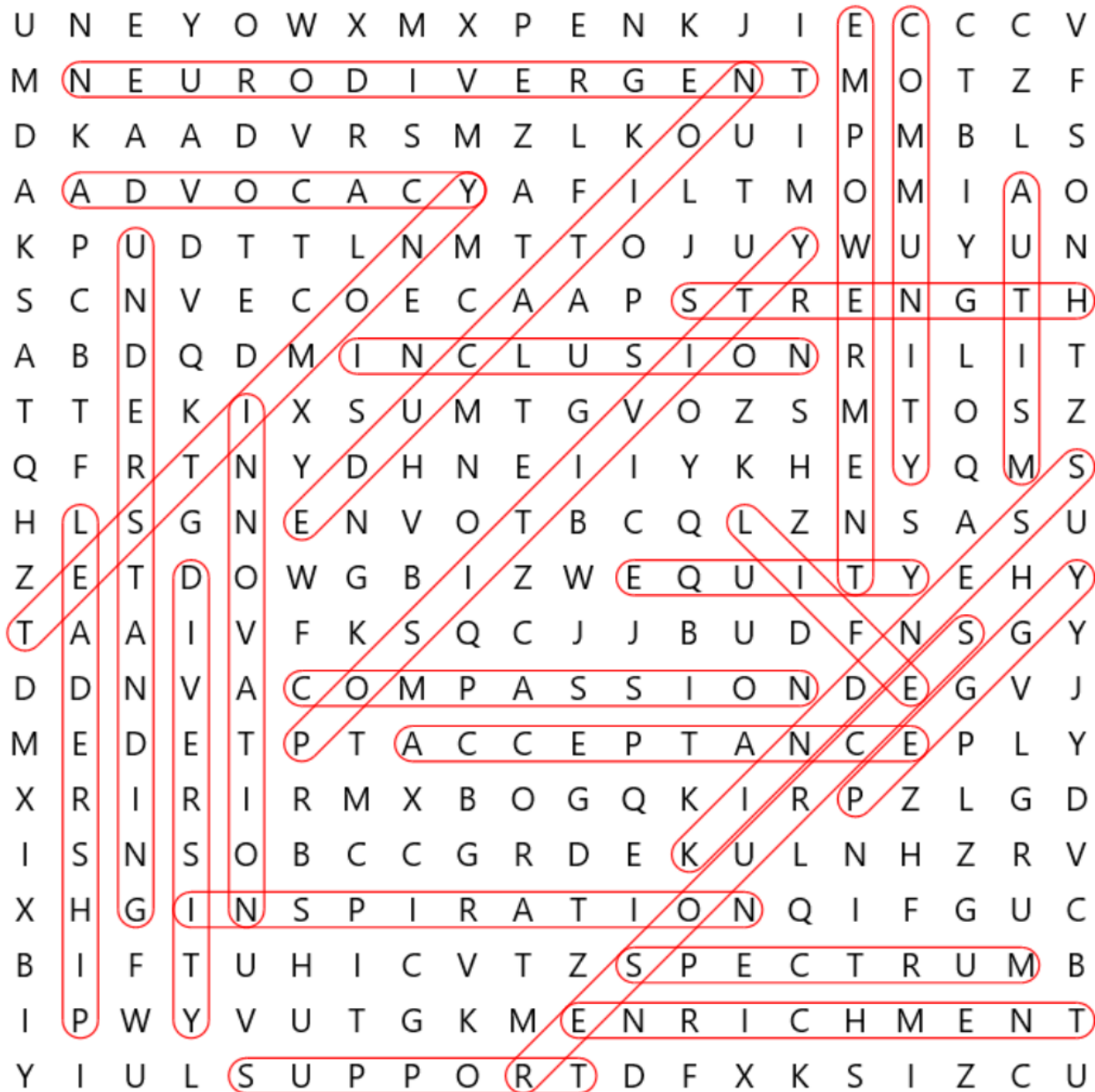
AUTISM EMPOWERMENT SEARCH

WORD

Acceptance Advocacy Autism Community Compassion Diversity	Education Empowerment Enrichment Equity Inclusion Innovation	Inspiration Kindness Leadership Life Neurodivergent Positivity	Resources Spectrum Strength Support Testimony Understanding
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Answers can be found at www.spectrumlife.org/wordsearch

Activity 1: Answer Key to Autism Word Search



The original Autism Empowerment Word Search puzzle was printed in the Fall 2024 issue of Spectrum Life Magazine. Each word in the puzzle represents a core principle that guides the organization's commitment to enriching the lives of individuals within the autism and neurodivergent communities.

<https://www.spectrumlife.org/wordsearch>

Activity 2: Community Awareness Activity

Community awareness initiatives are actions taken by individuals or groups to raise awareness about a certain issue, cause, or problem that affects the community. These initiatives can take various forms, such as campaigns, events, workshops, seminars, publications, or online platforms. The main goal of community awareness initiatives is to drive social change by informing, educating, inspiring, and mobilizing the community to take action, to make a difference in your local community.

1. Ask the participants to divide into groups of 4 to 5 people.
2. Group purpose: to discuss possible community activities or events to support individuals with autism or families with autistic members.
3. Each small group selects a recorder who will write down the ideas on newsprint.
4. Each small group selects a reporter who will share their ideas with the larger group.
5. Allow 2 minutes for the above instructions.

Allow 7-8 minutes for small group discussion.

Allow 6-7 minutes for small groups to share their ideas.

Possible Community Awareness Initiatives: Below are listed ideas that may be shared by the small groups. You may want to share any of these ideas that the small groups did not mention.

1. *Educate yourself to understand more about what autism is (and isn't) and how you can interact more effectively with individuals with autism. Read an article, read a book, watch a movie or television show on autism. (Marrone, p. 1)*
2. *Educate others in FCE Club/Unit or local community, sharing Hearth Fire #84 on Autism.*
3. *Become actively involved in supporting autism awareness and activities in your area. Become a volunteer with these organizations and events. For example, volunteer and/or participate as an individual or on a team in the Empower Walk and 5K Run fundraiser for the Autism Speaks organization. (Marrone, p. 1)*
4. *Show support during April, Autism Awareness Month, by wearing t-shirt, ribbon, etc. or posting support on social media.*
5. *Be an advocate. Stand up for children and adults with autism. Ensure that individuals with autism feel welcome, valued and are treated with respect. Be kind! (Marrone, p. 1)*
6. *FCE members may sponsor a workshop to make weighted blankets or fidget blankets for local children with autism. Invite friends and neighbors to participate too. (Marrone, p. 1)*
7. *Hold a fundraiser for a non-profit who serves individuals with autism. For example, a local equine therapy organization.*
8. *Volunteer for Special Olympics, Top Soccer, or adapted sporting event.*
9. *Speak up. Write or call your state representative, local legislators, or other leaders regarding proposed legislation that affects those with autism. Be aware of how these policies will impact access to services, insurance, research, and other issues. Encourage others to do the same.*

Handout for Activity 2: Community Awareness Activity

Community awareness initiatives are actions taken by individuals or groups to raise awareness about a certain issue, cause, or problem that affects the community. These initiatives can take various forms, such as campaigns, events, workshops, seminars, publications, or online platforms. The main goal of community awareness initiatives is to drive social change by informing, educating, inspiring, and mobilizing the community to take action, to make a difference in your local community.

1. Divide into groups of 4 to 5 people.
2. Group purpose: to discuss possible community activities or events to support individuals with autism or families with autistic members.
3. Select a recorder who will write down the ideas on newsprint.
4. Select a reporter who will later share the small group ideas with the larger group.
5. Be ready to share ideas with your small group and large group!

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