Life Journey Through Autism:
A Parent's Guide to Research

DANYA INTERNATIONAL

ORGANIZATION FOR AUTISM RESEARCH

Life Journey Through Autism:
A Parent's Guide to Research

By

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ORGANIZATION FOR AUTISM RESEARCH
Research and resources that help families today!

Dear Fellow Parents and Friends,

A Parent's Guide to Research was the very first resource we published back in 2003. OAR wasn't even two years old then. That original guide would go on to be the first of what are now nine publications in the *Life Journey Through Autism* series. We published it hoping that it would help parents, especially when first confronted with their child's autism diagnosis. As we publish this updated version, the difference between then and now is that we know from more than 15 years of constant demand that it is the tool for parents we had hoped it would be at the start—a useful resource to support them as they become familiar with their son's or daughter's diagnosis.

For parents of children with autism, there is one constant. From the moment your child is diagnosed, you need reliable information about this complex disorder. Most parents face a daunting learning curve when plunged into this new world of information replete with unfamiliar medical and scientific terminology. We quickly discover there is no single source or national clearinghouse for information on autism. It may seem unfair, but it falls upon us parents to educate ourselves. I understand how difficult this can be because I've walked that path. I have a son and daughter with autism, both now in their thirties.

When we founded OAR, one of our foremost objectives was to deliver practical information and tools to ease the burden on the front-line caregivers—mothers and fathers, brothers and sisters, grandparents, teachers, classroom assistants, and others who face the everyday challenges presented by autism. *Life Journey Through Autism: A Parent's Guide to Research* was the first and oldest resource until today. It's still the first, but now it is fresh and up-to-date.

A project like this does not happen without hard work by many people, starting with the original project team. That said, the credit for this version goes to Kimberly Ha, OAR research and programs director; and Nancy McIntyre, Ph.D., and Sallie Nowell, Ph.D., CCC-SLP, from the Frank Porter Graham Institute, who worked tirelessly on the project for the last six months.

The guide is designed to address the needs of parents of children just diagnosed with autism. It will help you ask better questions as you seek the best treatment for your child. It will not answer all your questions. Nonetheless, I am confident that it will be a useful guide for you and your child as you begin your life journey with autism.

Sincerely,

James M. Sack, Esq.
Chair
Organization for Autism Research

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Board of Directors

Staff

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Scientific Council

OAR's Scientific Council is comprised of 17 leading autism and medical professionals, and serves as an expert information resource for all OAR matters concerning issues of research. As such, the Council assists OAR's Board of Directors in developing its research strategy, near-term priorities, and long-range research objectives. The Council also provides program guidance and oversight for OAR's research competition, and plays a central role in ensuring the highest quality reviews for prospective OAR research proposals.

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American Legion
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Introduction

What Is Autism?

Autism spectrum disorder (ASD) is a developmental disorder that typically appears by 3 years of age and impacts an individual's ability to engage in reciprocal communication and social interaction skills, along the presence of repetitive patterns of thought and behavior. For example, common effects of the disorder include:

- Difficulty understanding social cues and figurative language
- Persistent preoccupation with objects or specific topics of interest
- Limited communication or repetitive speech
- Lack of eye contact
- Hyper- or hyposensitivity to external stimuli

The degree to which these areas of development are affected varies significantly. For example, some individuals have no verbal language abilities, while others have language capabilities similar to those of their peers. This variation in the severity of symptoms is often referred to as the *autism spectrum*. Throughout this guide, *autism spectrum disorders* will be referred to as autism. For detailed information on the diagnostic criteria for autism spectrum disorders, refer to the American Psychiatric Association's (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5).

How Many Children Have Autism?

According to the Centers for Disease Control and Prevention (CDC, 2018), approximately 1 out of 59 children in the United States is diagnosed with autism. The disorder affects children across all cultures and socioeconomic groups, but is four times more likely to be diagnosed in boys than in girls. However, recent studies indicate that a potential gender bias may be inherent in existing diagnostic tools. Therefore, there is a need to develop diagnostic tools that can accurately detect autism in girls.

What to Do When Your Child Has Been Diagnosed with Autism

For most parents, the diagnosis of autism may be emotionally challenging. You may feel overwhelmed by your child's diagnosis; it is natural and understandable that you feel this way. At the same time, you need to know that through informed action and the use of appropriate treatments and interventions, you can enhance the quality of your child's life.

Research being conducted in the field of autism has yielded options from which you and the professionals on your child's team can choose to support your child. While it is not yet possible to accurately predict how much progress a given child will make, the consensus within the medical and educational communities is that early intervention can greatly improve the quality of life for many children diagnosed with ASD. This guide will help you become a better consumer of information about autism.

What a Parent Can Expect Following the Diagnosis

Your child's diagnosis of autism may be difficult to understand and accept—not just for you, but also for siblings, extended family members, and friends of the family. Parents and other loved ones often experience a wide range of emotions after the diagnosis—from confusion to anger, from hope to despair.

Local parent groups are a great source of emotional support and guidance to other resources, not just right after the diagnosis but throughout your journey with autism. Attending informational sessions and meetings will not only raise your knowledge and skill level, but also enable you to develop a support network. Support may also be obtained from counselors or autism organizations at the local, state, and national levels, as well as social media groups. You will likely find the most direct support at the local level, with more comprehensive and general autism information available at the state and national levels. Contact information for some of the national autism organizations may be found in the Autism Resources section on page 37 of this guide.

Become an Informed Consumer of Information

It is necessary to spend a significant amount of time and effort in order to become a knowledgeable consumer of information regarding treatment claims. For example, general information on autism that can be found online may be full of false hope and anecdotal information. You are the primary advocate for your child until your child develops the necessary skills to advocate for themselves. As your child's advocate, it is important to be able to evaluate your child's needs as well as the research supporting various autism interventions that may be appropriate for your child.

There is no central resource for autism information. Compounding matters, opinions about the best methods of treatment may conflict. As a result, you must gather information from a variety of sources, including websites, mass media, research journals, reports from conferences and workshops, and education and health providers. In addition, networking with other parents and educational or medical professionals can help you identify sources of information that have been most useful to others. In short, what you choose for your personal approach will likely end up coming from a number of different sources and include a variety of approaches.

A word of caution: *Beware of those who claim to have a cure*. Your hopes for your child may leave you vulnerable to those marketing a variety of educational, medical, and other alternative treatments for autism that have no proof of effectiveness. Given your heartfelt wish to help and support your child, an emotional appeal from such promoters can be difficult to resist. Although many proponents of various treatments truly believe in their products or services, few fads or miracle cures hold up when scientifically tested. The time you and your child spend on researching and going through treatments is finite; use it wisely.

One purpose of this guide is to provide you with some basic tools for evaluating the validity of treatment claims. These tools can also be used to evaluate the research studies that support them. Specifically, the guide gives you a basic understanding of the purpose of research, how it is conducted, and the criteria to use when judging its value. Armed with this information, you are better equipped to ask the right questions of your child's doctors, therapists, and teachers about specific interventions or treatment options.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Centers for Disease Control and Prevention. (2018). Prevalence of autism spectrum disorders among children aged 8 years: Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *Mortality Morbidity Weekly Report Surveillance Summaries, 67*(No. SS-6):1–23. doi: https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm?s_cid=ss6706a1_w

How to Use This Guide

There is an enormous amount of published information about autism that can be found in books and online resources. While increased access to information is beneficial, too much information can be overwhelming when searching for specific answers to your child's everyday problems. Parents of children with autism face many challenges that arise from the practical, day-to-day issues of living with autism. *Life Journey Through Autism: A Parent's Guide to Research* has been written to serve as a resource for parents of children recently diagnosed with autism. The specific goals of the guide are to help parents:

- Find information about autism;
- Distinguish between research-based and non-research-based information;
- Become savvy consumers of information by giving them the tools to identify reputable research;
- Evaluate research studies using a framework that guides them through the process; and
- Interpret and apply research findings to their individual situation and needs.

Organization of the Guide

The guide is organized into five sections, as listed in the Table of Contents. We recommend that you start by reading the guide in its entirety. You can then refer back to a particular section, as needed, to guide you in your search for information on autism. In addition to the main sections, the guide also contains the following helpful information.

Glossary

Beginning on page 33, a glossary of terms defines terminology commonly used in autism treatment and research. Throughout the text, research terms defined in the glossary are marked in **bold** print.

Autism Resources

Page 37 provides a list of autism organizations. You can use this list to visit other websites to obtain information; get information about these organizations and available support groups; and sign up for their mailing lists.

Recommended Readings

You will find a recommended reading list on page 39. The books and research reports included in this section provide four types of information:

1. Basic information about autism,
2. Primary research studies about autism,
3. An overview of the current trends in autism research, and
4. Recommendations on how to read and evaluate research.

Appendices

- *Appendix A:* **Current State of Autism Research:** A brief summary of knowledge gained across a selection of research topics.
- *Appendix B:* **Participating in Research Studies:** Information about participating in research studies in an easy-to-use question-and-answer format.
- *Appendix C:* **Sample Research Articles:** Examples of five types of research.
- *Appendix D:* **Worksheets:** Printable worksheets for taking notes and evaluating research articles in a practical way.

How to be a Savvy Consumer of Sources of Autism Information

Being a good consumer of information on autism will require you to sift through a vast array of information. Amidst all the information out there, it can be difficult to distinguish between reputable and questionable sources. This section provides guidance on where and how to search for resources on autism and autism research, followed by suggestions for how to evaluate the information you find.

News, Social Media, and Blogs

Always be critical about what you read or watch in the news, whether it is online, on television, or in print. Even well-known and credible reporters may grossly simplify or misinterpret research. Reporters work in an environment that requires them to synthesize information from multiple topic areas in a short amount of time to meet publication deadlines. Thus, although they may not intentionally misinterpret research, in summarizing information for a general audience, they may overlook or oversimplify key points or limitations of research. In addition, reporters are more likely to interview people who have had extreme responses to a treatment—either finding it very effective or "miracle-working" or dangerously ineffective or harmful. Neither of these types of scenarios is likely to be representative of the average person who uses a given treatment approach. Therefore, make sure to review the original research article and ask a professional before deciding if a treatment discussed in a news article is appropriate for your child.

In 2018, the Pew Research Center reported that social media has surpassed print newspapers as a source of news information in the United States, and more than two thirds of adults use Facebook. Social media platforms, such as Facebook, Instagram, and Pinterest, use algorithms to determine the content that is most likely to be of interest to users. This means that if you have clicked on links or "liked" posts within social media, content related to those links will appear more often on your main page or newsfeed. That is, social media sites attempt to predict what you want to see in the future based on your past interactions with friends or brands. Unfortunately, this can put you in a vulnerable position because, for example, "liking" a post about a child with autism sleeping through the night can lead to a deluge of advertisements and articles on your newsfeed about sleep and autism—whether you want them or not.

The news disseminated via social media usually has short headlines that are overly dramatic, emotion-provoking, or sensationalized to entice consumers scrolling through their newsfeed to click and read more. They may promote fixes or cures for autism or autism symptoms. Some of them will even intentionally try to make you feel sad or angry to provoke you to read the information. Finally, news sources, websites, and blogs receive money from advertisers based on the number of clicks or reads their pages receive. Keep these points in mind when reading headlines on social media to stop yourself from wasting time and energy on non-trustworthy news sources.

Examples of Sensationalized Headlines

- The Essential Oil Blend That Cured My Child With Autism's Sleep Problems
- 5 Easy Ways to Prevent Wandering in Autism
- The Research-Based Approach to Reversing Autism
- Doctors Don't Like This Diet Because It Cures Autism
- 7 Secrets About Autism Your Doctors and Therapists Won't Tell You
- What is an Ion Cleanse and How Can It Help My Child with Autism

Parents of children with autism or other developmental disorders may write articles and blog posts with similar headlines. They may give testimonials about their experiences using products or resources that they want to share with other parents. Some parents use blogs to generate positive support and community around their experiences raising a child with autism, while others use blogs to vent about their challenges.

Humans have been sharing parenting success and failure stories like this for centuries, but in the age of social media, you are more likely to hear such stories from people you do not know. Keep in mind that bloggers typically are only writing about their individual experiences, and their perspective may be influenced by multiple factors. What works for one child does not necessarily work for all children. Furthermore, some bloggers receive products from brands and are paid to review them in their blog posts. Unfortunately, that is not always made clear to readers, which leads to confusion. To further complicate things, because social media users often click on sensationalized headlines, some credible news sources now use bold headlines to attract attention.

To filter through this information, use the following general guidelines for reading social media posts:

- **Look at who posted the article.** Is it someone that you know and trust? Is it from a group, organization, or news source that is credible, like a university-based autism program or federal department?
- **Avoid clicking posts that say "sponsored," "promoted," or "advertisement."** These words may appear in small print at the top or bottom of the post, so look carefully.

- **Think carefully before reacting to or sharing sensationalized posts.** Similar articles are more likely to show up in your newsfeed if you respond to that content.
- **Make sure that the article cites research studies or major autism organizations when stating facts about autism.** For example, if an article says, "studies show that children with autism have gastrointestinal disorders," does it tell you which studies so that you can check the facts?
- **Read with a critical eye.** If it sounds too good to be true or is overly emotion-provoking, the information is probably exaggerated.
- **Always ask a trusted researcher or medical provider** before paying for or trying a new treatment for your child.

Reference

Pew Research Center. (2018, December). *Americans still prefer watching to reading the news—and mostly still through television*. Retrieved from https://www.journalism.org/2018/12/03/americans-still-prefer-watching-to-reading-the-news-and-mostly-still-through-television/.

Beware of Unsubstantiated Claims of Success: There Are No Miracle Cures!

Every now and then, a claim about a revolutionary treatment for autism will appear. These claims show up in many forms, including:

- News articles or viral social media posts about new medical treatments;
- Broadcast news stories about new medical treatments; and
- Books written by parents about their child's "miracle" cure.

Before following up on any one lead, it is good practice to begin with some investigative research. This includes (a) searching through a reputable database such as PubMed to see if anything has been published about the treatment and (b) contacting the people making the claims and asking for literature about their work, including scientific publications. It is important to look into these claims to see if they are supported by well-designed research typically conducted at an academic institution.

> If there is no research supporting claims of "miracle" cures, they should be viewed with a healthy dose of skepticism.

Finding the Research

You will undoubtedly hear about autism research studies through news reports on television or in newspapers and magazines. Television, newspapers, and magazines report scientific research "second hand," in a brief way that is easily understandable to the public. In their reports, journalists may cite the author and name of the professional journal in which the research was published, but many of the details of the research may be left out. For the most part, journalists do a good job reporting the research, but it is important to remember that there is no scientific process to make sure that what journalists report is accurate. Therefore, to determine that the research is interpreted and reported accurately, it is best to get the report "first hand" by reading the original published research.

Professional journals report research by the scientists who conducted the studies and vary in quality and rigor. The research reported in journals is usually submitted through a process called "peer review." During a peer review, other researchers read and comment on the quality of the research, including whether it adheres to the ethical and quality standards of the profession, and then make a decision about acceptance, the need for revisions and reconsideration, or rejection. To determine if an article is published in a peer-reviewed journal, you can read the instructions to authors for submission of articles, which should describe the review process. There is a great deal of competition to publish, so articles that appear in journals have usually been examined very carefully. However, this does not mean that all limitations are identified; this typically does not happen until subsequent studies from other researchers are published. This guide will help you find these first-hand or original scientific publications and determine if they are applicable to your child.

Websites

Many websites cover the topic of autism; unfortunately, not all websites are good sources of information. Without some experience or training, it can be difficult to discriminate among websites. The websites for the national autism organizations provided in the list of autism resources on page 37 offer sound information on selected topics. Many of them also provide links to other sites and scientific articles on autism.

Some characteristics of websites that provide avenues to quality autism research include the following:

- Provide links to other major autism organizations, academic research institutions, and professional research articles;
- Hosted by government agencies or educational institutions (which often end in .gov, or .edu); and
- Clearly cite sources of information.

Examples of websites that provide access to quality autism research and resources include:

- *Association for Science in Autism Treatment:* https://asatonline.org
- *Centers for Disease Control and Prevention,* section dedicated to research on ASD: https://www.cdc.gov/ncbddd/autism/research.html
- *National Institute of Child Health and Human Development (NICHD) Newsroom*: https://www.nichd.nih.gov/newsroom/news?topic=autism
- *Spectrum,* an independent website covering autism research news that originated as part of the Simons Foundation's website (SFARI.org): https://www.spectrumnews.org
- *Medline Plus,* a National Institutes of Health website that provides up-to-date health and wellness information: https://medlineplus.gov/autismspectrumdisorder.html
- National Professional Development Center on Autism Spectrum Disorders, a collaborative project that identifies evidence-based practices for individuals with ASD: https://autismpdc.fpg.unc.edu/national-professional-development-center-autism-spectrum-disorder

Searchable Online Databases

Searchable online databases are very good sources of information about autism research. Some databases (such as PsychInfo, compiled by the American Psychological Association) are for members only and are only accessible to the public through university libraries. Two searchable databases available to the public include PubMed (Medical Publications) and ERIC (Education Resources Information Center).

PubMed is maintained by the National Library of Medicine at the National Institutes of Health; it contains an extensive collection of scientific medical and psychological literature.

PubMed is located at http://www.pubmed.gov.

ERIC is supported by the U.S. Department of Education, Office of Educational Research and Improvement, and the National Library of Medicine; it contains an extensive collection of publications in the field of education, and is an excellent source of school-based research.

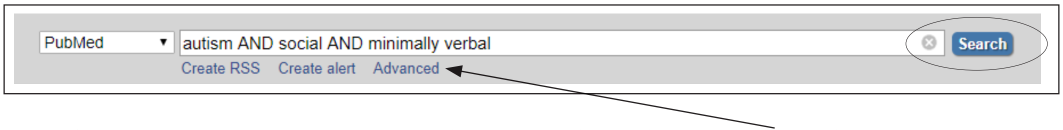
ERIC is located at http://www.eric.ed.gov.

Online databases are designed to help users retrieve information using the "keyword" system. This means that when a user enters a word, the database retrieves all articles that contain that word. The advantage of this system is that it is very easy to use, but the disadvantage is that it retrieves more information than the average person needs or can possibly review. For example, by entering the keyword "autism" into PubMed, the system retrieves more than 45,000 articles!

Therefore, the challenge to users of online databases is learning how to narrow down a search so that only articles of interest are retrieved. This usually requires some trial-and-error practice using the databases. Below are some tips for narrowing an online search using PubMed and ERIC.

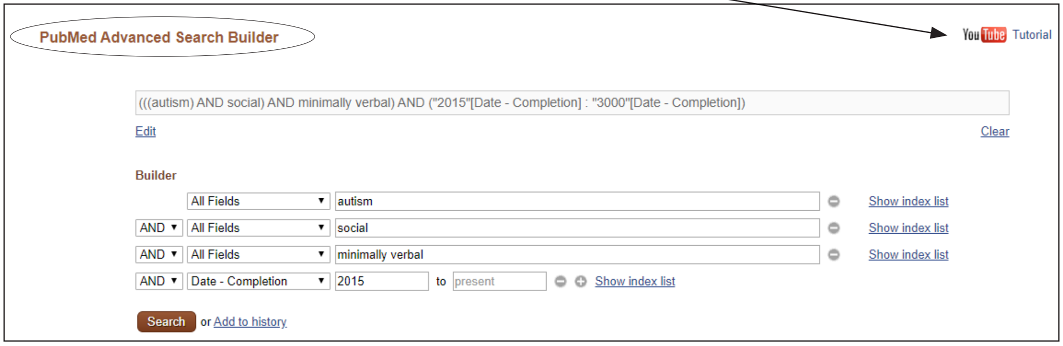
Tips for Searching PubMed

- Enter keywords such as "autism" and "social" with the word "and" between the words to narrow a search; if too many references are retrieved, you can add another keyword to the search, such as "minimally verbal"; if too few references are retrieved, you can delete a word.



autism AND social AND minimally verbal

- Another way to narrow a search is to select the "advanced" option on the home page, which allows a search to be narrowed by limiting the publication date, author, population, field, and so forth. If you need additional assistance, the website offers a video tutorial on how to use the advanced search engine.



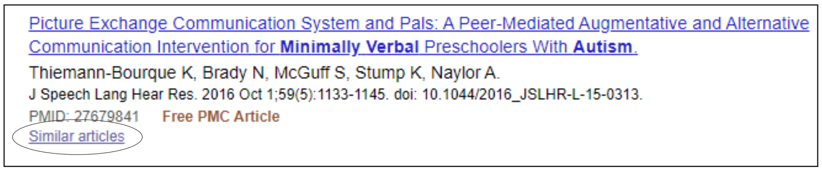
PubMed Advanced Search Builder

(((autism) AND social) AND minimally verbal) AND ("2015"[Date - Completion] : "3000"[Date - Completion])

Builder

All Fields: autism
AND All Fields: social
AND All Fields: minimally verbal
AND Date - Completion: 2015 to present

- On the search results page, if an article is related to a topic of interest to you, click on the "similar articles" option, or try entering the author's name in the author field of the "advanced" option to retrieve similar articles. Authors typically publish more than one article on a topic.



Picture Exchange Communication System and Pals: A Peer-Mediated Augmentative and Alternative Communication Intervention for **Minimally Verbal** Preschoolers With **Autism**.
Thiemann-Bourque K, Brady N, McGuff S, Stump K, Naylor A.
J Speech Lang Hear Res. 2016 Oct 1;59(5):1133-1145. doi: 10.1044/2016_JSLHR-L-15-0313.
PMID: 27679841 Free PMC Article
Similar articles

Tips for Searching ERIC

- Click "Advanced Search Tips" for a video and tips on how to use the *ERIC Database*.
- Select the "Collection" option on the home "Search ERIC" page to enter keywords. If too many references are retrieved, add another keyword; if too few references are retrieved, delete a word.
- Choose the "Thesaurus" option on the "Search ERIC" database page, enter a search term, then select "Include synonyms" and "Include dead terms." The search engine converts search terms into similar indexed terms in the thesaurus. For example, the key term "autism" will yield "autism spectrum disorders," which will yield "pervasive developmental disorders" as a result.

Medical and University Libraries

Medical school and university libraries own large collections of professional journals. The general public is usually welcome to browse these journals and make photocopies of articles to take home. The holdings of these libraries are also accessible online, not only to staff and students at these institutions but also to the general public upon request.

The most recent issues of professional journals are usually kept in the reference section of the library. Past issues are generally housed together with book collections in the library. The reference librarian is your best source of help for locating these journals.

Local public libraries may accept interlibrary loan requests for items they do not own. These requests may take several weeks to process and ship, and may have an associated shipping or print charge.

Contacting Individual Researchers

Once you begin, you may discover that researchers often publish articles in an area of interest. Most autism researchers are happy to provide reprints of their articles to interested parents. The best way to contact researchers is through email. When you locate the email address of a researcher, ask them to send PDFs of the article(s) you would like to obtain.

Tips for Finding Contact Information for Researchers:

- In articles published in recent years, contact information, including an email address, is usually provided on the bottom of the first page of the article or at the end of the article near the reference section.

- The abstract of an article is another source of author contact information. The abstract usually provides the author's institution or affiliation, which is most likely a government agency, private company, or university. Authors from government agencies and private companies can often be contacted by email from the agency or company website.
- Researchers at universities can often be located by conducting a "person" search on a university website. Typing the name of the university using any search engine (such as google.com or bing.com) will take you to the website.

Understanding the Scientific Model

Reading and interpreting research can be a difficult task for a beginner. However, with perseverance and practice, you can learn to comfortably navigate scientific writing for the purposes of making informed treatment decisions for your child. This section is written to give you a basic understanding of the scientific model underlying research studies.

What Can Research Do?

Before examining the structure of individual research studies, it is helpful to understand science and research as a whole. Science is the iterative and systematic process of studying the nature and behavior of natural things. As such, scientists make observations, ask questions, and generate and test hypotheses through well-designed studies in order to draw conclusions and pose new questions. Science is often a decades-long process of acquiring new information that builds upon previously gained knowledge and adapts it into existing frameworks. Many studies from different locations using different methods that converge on the same results are needed for the findings to be accepted within the research community. Study findings may be tentative until they are sufficiently reinforced or rejected through future research. For this reason, it is important to get a broad reading of many research studies, not just a few.

For example, scientists have observed developmental differences between infants who are typically developing and infants who are at high risk for autism. Based on the research community's collective findings in this area, screening tools have been developed in an effort to detect early indicators of autism among children in the general population. The next step, then, is to evaluate the implementation and quality of these screening tools, and conduct follow-up studies to improve them, as necessary. More specifically, if it is found that certain screening tools are more or less sensitive to gender differences, for example, researchers may go on to develop more sensitive screening tools designed to be used with that population, and then test the effectiveness of those. Through unbiased and iterative research, we are able to solidify our understanding of autism and improve existing tools and interventions.

The Difference Between Basic and Applied Research

There are two kinds of research: *basic* research and *applied* research. Both types of research are necessary to advance science and apply the findings to the benefit of society.

Basic research is designed to answer questions about a fundamental or basic problem for the purpose of advancing knowledge. Applied research, on the other hand, is concerned with solving practical, everyday problems, often by applying the knowledge gained through basic research.

For instance, through basic research, we might learn that children with autism who have adequate verbal skills need less support in an academic setting than children with poor verbal skills. Using this information—gained through basic research—an applied researcher might then design a study to see if a particular intervention program designed to increase verbal skills in preschool children with autism increases their readiness for school.

Basic research is usually conducted in a laboratory or clinical setting, such as university and medical laboratories. Applied research, on the other hand, is usually conducted in everyday settings, such as homes, schools, and other community settings.

Examining a Study

A research study is designed to investigate a particular topic. A study begins with a research question, such as: "How does the play behavior of children with autism differ from the play behavior of typically developing children?" Once a research question has been posed, the researcher designs a study to attempt to answer it.

Five Basic Types of Research Studies

There are five basic types of research studies, each designed to answer different kinds of questions. The five types (A–E) of studies are discussed below. (Appendix C provides an example of each type of study.)

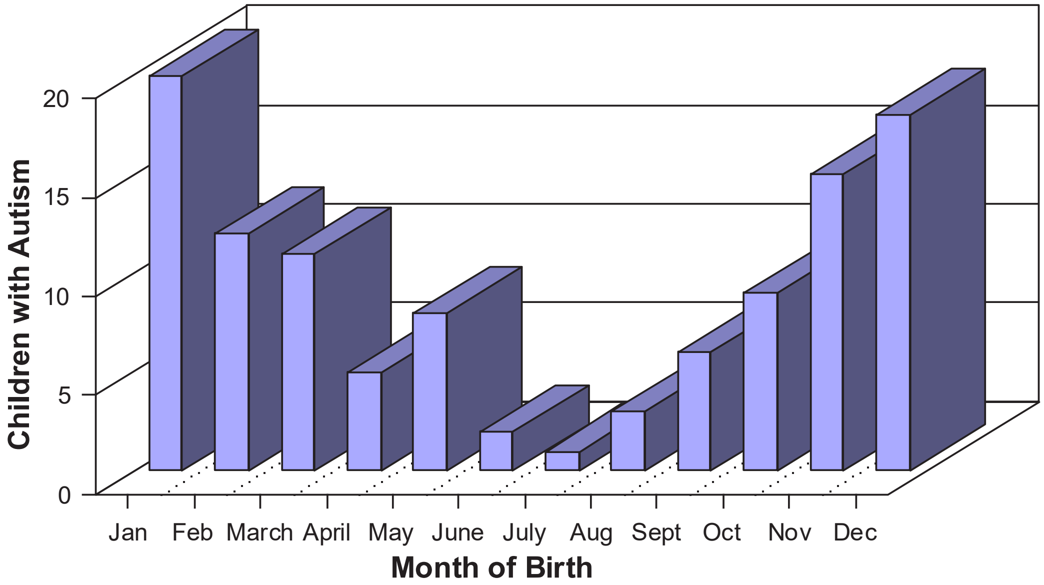
A. **Case Studies:** Case studies look at a single subject (e.g., a child with autism) or a single case (e.g., a classroom for children with autism). Case studies are typically used in research that describes the development of an individual, group, or situation over a period of time in order to provide a detailed account of what is occurring within its real-life context.

- The **advantage** of a case study is that it allows the researcher to gather a lot of information about one person or one case.
- The **disadvantage** of a case study is that the information gathered about one person or a small group of people cannot readily be applied or **generalized** to other people or other cases in other situations or other settings and, therefore, may be of limited use.

B. **Correlational Studies:** Correlational studies look for a relationship between two or more variables, or things, that naturally occur in the same environment. Correlational studies cannot tell us anything about cause and effect, only that there is a relationship between two or more things. For example, a study might be designed to determine if there is a relationship between the number of children with autism in a particular community and the month of their birth. Figure 1 presents a bar graph of a study of number of children with autism and month of birth. The graph illustrates that more children with autism were born in the winter months (November, December, and January) than in the summer, spring, or fall.

Correlation = / = Causation

Figure 1. Correlational study: Children with autism and month of birth.

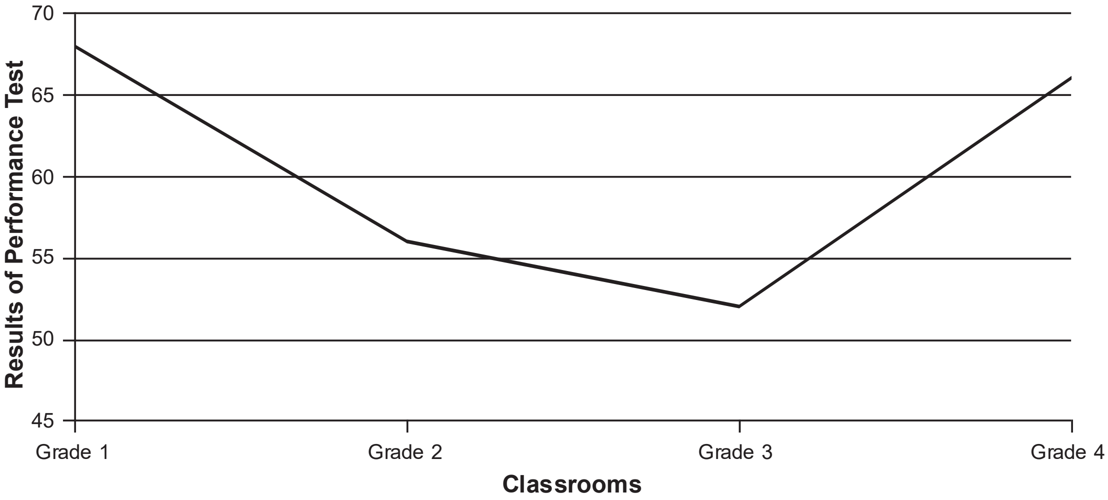


Although this graph shows a relationship between cases of autism in one community and month of birth, we cannot make the assumption that a winter birthday causes autism. Perhaps some other variable that we have not considered (such as an illness) is having an effect on the two variables under study.

- The **advantage** of correlational studies is that a lot of information about a large number of people can be gathered at one point in time.
- The **disadvantage** of correlational studies is that it is not possible to control other factors outside of the study that might influence the research.

C. **Longitudinal Studies:** Longitudinal studies can give us information about how people develop over time. These types of studies follow one group of people (referred to as a **cohort**) across time, measuring the same behavior multiple times. For example, we may want to determine if children with autism do better on performance tests in self-contained than in inclusive classrooms. The best research design for answering this question would be to follow one cohort of children with autism that spent time in both environments. In Figure 2, this design is presented with a line graph.

Figure 2. Longitudinal study: Self-contained vs. inclusive classrooms.



As illustrated in the graph, children in this cohort performed better in grades 1 and 4 when they were in inclusive classrooms than in grades 2 and 3 when they were in self-contained environments.

- The **advantage** of longitudinal studies is that they allow researchers to pinpoint times during development when changes occur.
- The **disadvantage** of longitudinal studies is that it takes a long time to complete them. (Note that in the example in Figure 2, the study took four years to complete.)

D. Experimental Studies: Experimental studies are used to study cause and effect. Experiments are controlled so that the researcher **manipulates** one variable to determine its effect on other variables. Two primary types of experimental studies are used in intervention development and testing: *randomized group design* and *single-case design.*

The first type includes experimental group designs in which participants are **randomly assigned** either to receive the intervention (the **experimental**

group) or to a **control group**. The control group completes all the same steps as the experimental group, except they do not receive the intervention that is under investigation. Therefore, if the study is well controlled, it can be concluded that the differences between the experimental and control groups at the end of the study are due to the intervention.

A common type of experimental study is an intervention study testing the effectiveness of a treatment program on outcomes such as performance scores. Using the above example, the intervention that is manipulated by the researcher is the "educational program." In this study, subjects in the experimental group would receive the new intervention program, while subjects in the control group would receive a standard (or "services as usual") program. The purpose of the study would be to determine if the test scores of students receiving the new intervention method would be higher than the scores of the students receiving the standard method.

- The **advantage** of randomized experimental studies is that the research design allows researchers to examine cause-and-effect relationships.
- The **disadvantage** of a randomized experimental study is that the results cannot always be generalized to the real world. This is because this kind of study lacks "real-world" authenticity; that is, what occurs in a controlled environment of a study may be very different from what might occur in a real-life setting, such as a typical classroom.

A cornerstone of experimental group design research is the concept of randomization. That is, participants are **randomly assigned** from the population to either the experimental group or the control group so that the groups will be exactly the same. Only if the groups are exactly the same can the researcher determine if the differences between them at the end of the study are due to the intervention. Figure 3 illustrates the randomized experimental method of research.

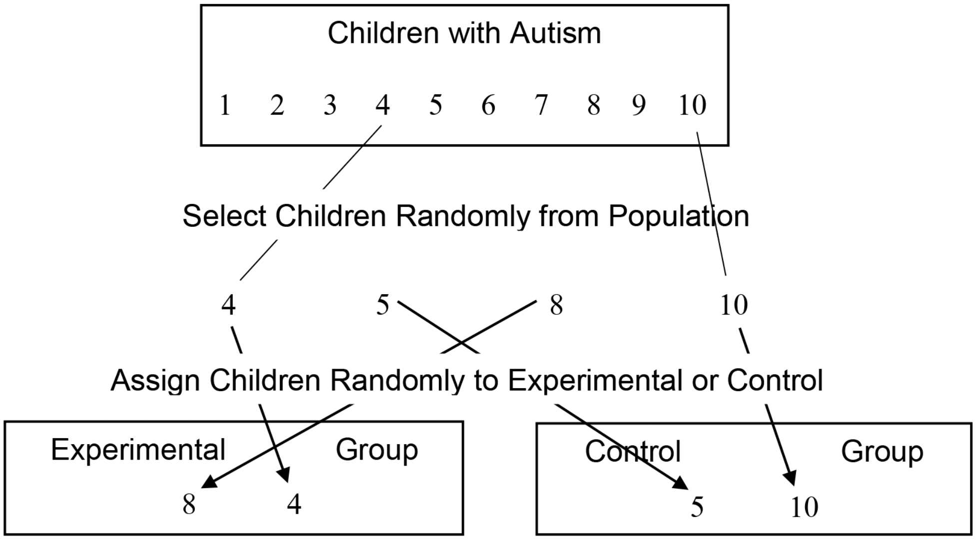
A second type of experimental study frequently used in intervention research is **single-case design** (SCD). Many studies involving children with autism, particularly those examining behavioral and educational treatments, use single-case designs. Rather than examining differences across participant groups that do and do not receive an intervention, single-case designs involve individual participants or a small cluster of participants who provide their own control for comparison. For example, a researcher may be interested in determining whether a new communication intervention tool on tablet devices improves communication skills.

First, the researchers might enroll three children in the study and collect baseline data by measuring their usual communication performance over multiple days (**baseline phase**). Second, the researchers deliver the intervention daily as the children receive the intervention and communicate using the tablet computer (**intervention phase**). Third, the researchers repeat the cycle by returning to baseline (no tablet device), and finally, fourth, they conduct a second intervention phase using the tablets.

Data collected and graphed for each individual over the duration of the study can indicate whether the tablet device helped the child communicate more effectively. The What Works Clearinghouse (www.ies.ed.gov) has established guidelines for evaluating SCD research. Currently, in order to provide a basis for making causal inferences about the effectiveness of an intervention, at least five high-quality SCD studies conducted by different research teams must be in agreement.

E. **Clinical Trial Studies:** Clinical trial studies are one specific type of randomized group experimental study. Clinical trial studies are most likely to be conducted in medical or other clinical settings. Similar to experimental group design studies, clinical trial studies employ an experimental/control group, in which participants are randomly assigned to receive the experimental treatment (e.g., a medication to treat autism symptoms) or a **placebo** (a sugar pill).

Figure 3. The randomized experimental method of research.



In both randomized experimental group and clinical trial studies, participants are not informed about their group assignment to guard against participant expectations about intervention or treatment. In addition, in well-designed studies, experimenters are not informed about group assignment either to guard against researcher expectations about intervention or treatment. That is, if participants expect to get better because they know they are receiving treatment, they may actually get better; similarly, if researchers expect an intervention to be successful, they may perceive it as so, regardless of whether or not the treatment is actually effective! This uninformed state is what researchers refer to as being blind to the conditions of the experiment. When both participants and experimenters are uninformed, it is referred to as a double-blind study, and is a means of ensuring objective results.

- The **advantage** of clinical trial studies is that they can determine the effectiveness of an intervention. This is because the intervention is compared with a placebo or control condition.
- The **disadvantage** of clinical trial studies is the same as for randomized experimental studies; that is, the results of the study cannot always be generalized to a real-life setting.

Where Is the Evidence?

Many different types of interventions, programs, and practices have been developed to address the challenges that autism presents. However, not all of these practices are supported by scientific research. Current laws governing the U.S. education system require the use of evidence-based practices in schools. Similarly, many health insurance providers determine reimbursement rates for health services based on the extent to which these are evidence-based.

Understanding which practices are backed by scientific research is an important starting point for selecting an educational or medical treatment. The following is a list of definitions to help you understand how systematic research translates to practical implementation.

Evidence-based research (EBR) uses previous research in a systematic way to inform the development of new research to ensure that it is answering valid and relevant questions in an efficient manner.

Evidence-based practices (EBPs) are interventions that researchers have shown to be effective through an accumulation of evidence from multiple high-quality scientific studies. While many interventions have been created for children with ASD, scientific research has found that only some of them are effective when implemented correctly in school or clinical settings.

Research-based practices (RBPs) are interventions that are backed by theories but have not been shown to be effective. That is, components of the intervention may have *some* research behind them that demonstrated they are effective, but the intervention as a *whole* has not been demonstrated to be effective by independent, rigorous research. The term RBPs is sometimes used interchangeably with EBPs, but the two are not the same. Although RBPs may hold some promise, there is not enough evidence (i.e., a sufficient number of high-quality studies with consistent results) to suggest that they are effective.

Anecdotal evidence is merely the testimony that something is true or false based on isolated examples of personal experiences. When you see a claim about a product or intervention that is based on the claims of one or more individuals' experiences, it means there is no scientific evidence that the claim is true.

Systematic reviews synthesize information gathered across many individual studies conducted to answer the same question. The evidence of effectiveness is gathered across multiple studies and is combined to provide a comprehensive summary. Many clinicians use systematic reviews to inform their practice, as a single study is not sufficient to show that something is effective. An accumulation of evidence is necessary to say with certainty that a practice is evidence-based.

It is also important for practitioners to use the best research evidence possible to make decisions about the care of an individual patient or student. This evidence is integrated with clinical expertise, patient values, and preferences. Your child's education and healthcare providers should be practicing in this manner.

Here are some helpful websites that show what has been effective and for whom:

- For educational EBPs:
    - National Professional Development Center (https://autismpdc.fpg.unc.edu/evidence-based-practices)
    - What Works Clearinghouse (https://ies.ed.gov/ncee/wwc/)
- For medical and therapeutic EBPs:
    - PubMed (https://www.ncbi.nlm.nih.gov/pubmed)
    - Google Scholar (https://scholar.google.com)
- UK's National Institute for Health and Care Excellence (https://www.nice.org.uk/)
- Canada's National Collaborating Centre for Methods and Tools (https://www.nccmt.ca/about/eiph)

Example of How to Search for Research Evidence

If you are interested in the scientific evidence for chelation therapy used with individuals with autism, for example, you can go to PubMed or Google Scholar and type in "systematic review autism chelation." You will see that a couple of systematic reviews have been conducted in the past several years. Just by reading the abstract summary of the systematic review, you will see that the authors have concluded that the evidence does not support this therapy.

Systematic reviews allow you to maximize your research time by giving you a broad overview of a large body of scientific literature; if a particular study is mentioned that you are interested in reading further about, you can search for it and examine for yourself whether or not it is relevant to your child's needs.

A Uniform Framework for Evaluating Research Studies

Most professional journals that publish research studies use a standard format for reporting research. This section will help you read and analyze research articles by providing you with a framework for evaluating them. First, it is helpful to know that the standard structure of a research article consists of six sections in the following order: (1) Abstract, (2) Background or Introduction, (3) Methods or Methodology, (4) Results, (5) Discussion, and (6) References. You may find that some journals use a different format; nevertheless, you can still use this standard format as a guide for evaluating a research article. As you review research articles, use the sample worksheets in Appendix D to help you summarize and critically evaluate them.

Abstract

The abstract of an article presents a summary of the research study. Its purpose is to provide the reader with a brief overview or synopsis of the article. As a general rule, the abstract contains a sentence or two from the first five sections of the article (see above), and usually includes the following key points:

- The purpose of the study, or why the authors think it was important to conduct this specific research
- Information about the participants in the study; their ages, ethnic background, etc.
- The research procedure used in the study
- The major results or findings of the study
- A summary of the findings of the study and why they are important

Often, as a first step in conducting research, the only section from an article that is needed is the abstract. The abstract usually provides enough information for you to decide whether the article is relevant to your child.

Background or Introduction

Research articles usually begin with some background information about the topic (e.g., autism) and the specific research areas related to the study. Key points to look for in this section include:

- *What has previous research found about the topic?*
- *How will this study add to the previous research?*

A research study is not carried out in isolation; it is connected or related to other research. Therefore, research articles begin by summarizing previous research on the topic of interest to provide a framework or add context for the present study. When referring to other research, authors cite the author and date of publication of each study, either in the text or at the end of a sentence, as illustrated in the box below. The full reference is then provided in the references section at the end of the article. So, if during your reading you come across a previous study that sounds interesting, you can retrieve the full reference at the end of the article.

An Example of Background Information
In a previous study, Jones, Meyers, and Klein (2017) found that children with autism take longer to learn new tasks than other children. This finding has been confirmed in other numerous studies (Brown & Rogers, 2014; Roberts, 2005; Williamson et al., 2016).

After summarizing previous research, authors state how their study adds to other research that has already been done.

- *What is the research question and hypothesis guiding the study?*

Typically, authors state their research question(s) in the introduction and make a hypothesis about what they expect the study to find. A research question states the topic broadly, while a hypothesis makes a specific prediction about what the researcher expects to find. Authors design a research study to answer a research question and/or test a hypothesis. A study can answer one or more research questions. The boxes below provide examples of a research question and a hypothesis.

An Example of a Research Question
Does early intervention make a difference in the need for special education services once children with autism are in elementary school?

An Example of a Hypothesis
If children with autism receive early intervention, then they will be less likely to need special education services in elementary school.

Methods or Methodology

The purpose of the methods section is to provide readers with a blueprint of how the study was designed and conducted. This section is usually divided into subsections of (1) research design, (2) subjects, (3) procedure, and (4) measures and instruments.

Research Design

This section tells the reader about the design of the study. Things to look for include:

- *What type of study was used in the research?*

Sometimes, the authors tell the reader what type of study they used (case studies, longitudinal studies, experimental studies, etc.). Often, however, the type of study is not explicitly stated, but clues will be evident in the study design. See Appendix C for examples of the different types of studies.

- *Where was the research conducted?*

Was it conducted in a laboratory, clinic, or "real-world" setting?

Subjects

This section tells the reader about the people who participated in the study. Important points to look for include:

- *How many subjects were included in the study?*

With the exception of case studies, which are frequently based on only one subject or one case, it is important to know how many subjects were used in the study. As a general rule, the more subjects that were involved, the more representative they are of the population under investigation.

However, it is important to bear in mind that research involving people with disorders such as autism generally have fewer subjects than studies that use participants from the general population. This is because there are simply fewer people with autism overall.

- *What are the characteristics of the subjects in the study?*

It is important to know something about the characteristics of the subjects in the study, such as their age and gender, to determine if they are representative of the larger population under investigation. For example, we know that among children with autism, four boys are diagnosed to every one girl. Therefore, we would expect a valid and reliable study on children with autism to show a similar ratio.

It is also desirable to have a racially and ethnically diverse group of subjects. With special populations, however, it can be difficult to recruit a diverse group of participants. In addition, many studies are conducted in laboratories or special schools where participants volunteer to participate. In such cases, the subjects are **self-selected**, and may not be representative of the general population.

- *What are the inclusion and exclusion criteria for subject selection?*

As a general rule, autism research studies should include all eligible participants and verify their diagnosis. However, in some circumstances, certain people might have to be excluded. For example, a study might want to look at the characteristics of boys and not girls. Sometimes individuals with other diagnoses such as attention deficit/hyperactivity disorder (ADHD), anxiety disorder, seizure disorder, psychosis, or other co-occurring disorders are specifically included or excluded, depending on the research question of a study or the specific segment of the population of individuals with autism the researchers want to better understand. Regardless, if the study excluded some possible participants, it should clearly state the reasons why they were excluded.

- *How were the participants assigned to groups?*

If there is more than one group in the study, the methods section should explain how the participants were assigned to each group. Sound research studies "randomly assign" participants to groups. **Random assignment** is a lot like "flipping a coin," meaning that each participant has an equally likely chance of being assigned to any one group. The purpose of random assignment is to guard against **bias** in assigning participants to a group, which might affect the outcome; that is, to ensure that there are no differences in the basic characteristics of participants in any one group compared with those of any other group. Without such safeguards, the results might not be valid.

Procedure

The procedure section explains how the study was conducted. Important things to look for regarding how the research was conducted include:

- *What steps did the researchers take to set up and complete the study?*

This section should give a fairly detailed explanation of the procedure used in the study, including the method of collecting data. The purpose of this section is to enable others to recreate the study exactly as conducted, given the necessary equipment or skill.

- *What kinds of data were collected?*

The procedure section should also give specifics about what kinds of data were collected from the participants, such as measures of knowledge or behavior. A sound study collects sufficient data to test all the hypotheses or answer all of the research questions posed at the beginning of the study.

Measures and Instruments

This section should provide specific information about the **instruments and measures** used to collect the data. Specific points to look for in this section include:

- *Do the instruments measure what they are supposed to measure?*

Researchers should discuss whether the instruments measure what they are supposed to measure. In research terminology, this is referred to as **validity**. Authors talk about validity in numerical terms, expressed as a decimal (e.g., .80). A perfectly valid instrument will have a validity of 1.0. Generally, instruments above .75 are considered to have good validity. However, a lower score may be considered acceptable if other studies have used the instrument successfully.

- *Have other researchers used the instruments?*

Generally, instruments that have been used by other researchers have more credibility than others. Authors should refer to other studies that have used the same instrument by citing the author and the date of publication of the study in the text. If it is a new measure, not used in other studies or created specifically for the study at hand, the authors should give a lot of detail about the measure, as well as an explanation for why it was chosen for use in their study.

Results

The results section explains the statistical analyses of the data conducted as part of the study, and presents the findings of the analyses in three formats: (1) narrative (written in text), (2) graphic (depicted in graphs/figures), and (3) tabular (presented in tables). Key points to look for in this section include:

- *What are the findings of the study?*

Research studies use sophisticated statistical methods to evaluate their findings. The average layperson (and even some researchers!) may be unable to evaluate the more complex statistical methods used in conducting research. Therefore, the best strategy for evaluating the findings of a given study may be to get a general idea by looking at the tables and figures provided.

The **tables** present the average or mean scores for each group on the measures used in the study. By looking at these scores, you can get a general idea of whether one group scored notably higher or lower than another. An example of a table presenting mean scores is provided below. The table tells us that the maximum score on the measures is 100. On the verbal skills test, the experimental group scored higher than the control group (82 vs. 71). The asterisk after this score shows that the difference is **statistically significant**. On the spatial skills test, the experimental group again scored higher than the control group (70 vs. 68), but this difference is not as large and, therefore, is not statistically significant. (See the next section for more about statistical significance.)

Mean Score Differences on Verbal and Spatial Skills Tests (Max. Score 100)

	Experimental Group	**Control Group**
Verbal Skills	82*	71
Spatial Skills	70	68

*$p < .05$.

The **figures** present the same information as the tables, but in a graphic format (often figures are presented as bar graphs, as illustrated in Figure 1, or as line graphs as illustrated in Figure 2). By looking at the exhibits, the reader can see if there is a general pattern in terms of which group differs from another.

Not all studies present the findings in both tabular and/or graphic formats. Therefore, sometimes readers will have to interpret the findings as best they can by reading the text.

- *What do the findings mean?*

Differences in group scores do not necessarily indicate that the findings are significantly different. In research, the findings are considered meaningful only if they are "statistically significant." Findings are considered statistically significant if the probability that the difference in scores is due to chance is less than 5%. In research studies, statistical significance is expressed in text as "$p < .05$" or "$p < .01$."

Note that being statistically significant does not automatically make the findings clinically significant. That is, the findings must be considered within the context of clinical norms.

The discussion section explains the findings of the study in terms that are more easily understandable to the layperson than the results section.

Discussion

In the discussion section, researchers summarize the findings of the study, give their interpretation of the findings, and present their conclusions about the study. Key points to look for in this section include:

- *How do the authors summarize their findings?*

The discussion section should begin with a summary of the findings. Most authors summarize the findings in the first paragraph of this section.

- *How do the authors interpret the findings?*

The discussion section gives authors the most "flexibility" because the findings of a study are always open to interpretation. Authors usually present a very good argument for their conclusions about the findings of a study.

> It is important to bear in mind that the discussion section of an article reflects the authors' own interpretation of the findings of the study.

- *What are the limitations of the study?*

In addition to presenting their conclusions about the findings, authors should also discuss the limitations of their study. For example, was it limited by a small number of participants, or to a specific setting?

- *Are the findings applicable to different participants and other settings?*

Authors should also discuss whether or not the findings are applicable to different participants and other settings. This will depend on the characteristics of the participants used in the study and whether or not the setting is applicable to the real world or is limited to a laboratory setting. The researchers may end the discussion section by suggesting what research still needs to be done in order to answer the question more fully.

References

As stated previously, research does not occur in isolation. Authors conduct a literature review of relevant studies before conducting a study and share their relevant findings in the background or introduction of the article. A literature review summarizes the existing body of published articles and other sources relevant to the study topic. It demonstrates the authors' understanding of the research topic, and provides context for the purpose of their own study.

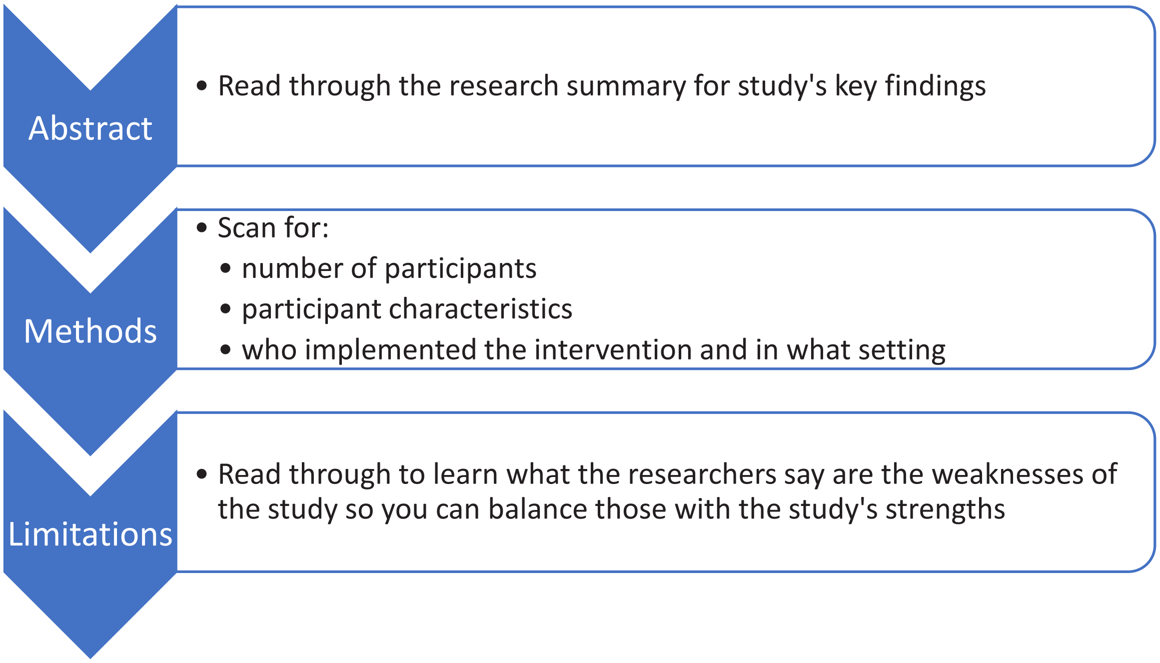
In the references section of the article, the authors list all research studies that they cited in the article. If you want to look up a reference to learn more, you can search the author's name or study title in an online database.

Beware of a Conflict of Interest

As an educated consumer of information, it is important to be aware that researchers are sometimes influenced by a "conflict of interest." For example, drug companies may offer funding to researchers to conduct studies testing their products. And, because their research is dependent on the company for funding, researchers can be under pressure to find evidence that supports the use of these products. Conversely, negative results may be suppressed. Therefore, it is always wise to investigate the source of funding behind the research. In most professional research articles, authors acknowledge their source of funding by referencing the funding agency and grant number, where applicable, either on the first page or right before the reference section at the end of an article.

How to Scan for Research Articles

If you have limited time to read a full research study, reading the article's abstract will provide you with a synopsis of the key points of the study and allow you to determine whether to read further. If it looks interesting, scan the methods section to learn more about the participants in the study to see how many there were, if they share characteristics (e.g., age, gender, verbal ability) with the population in which you are interested, and who implemented the intervention in the study (e.g., parents, teachers, researchers, clinicians). This will help you determine the extent to which you can relate the study's findings to your own questions. Finally, as mentioned, most studies include a limitations section at the end (before the reference list). This is a helpful section to read because this is where the researchers point out any aspects of the study that you should be cautious about. No research study is perfect, so a thoughtfully written limitations section can help you understand the weaknesses of the study and balance that with its strengths.



Abstract

- Read through the research summary for study's key findings

Methods

- Scan for:
  - number of participants
  - participant characteristics
  - who implemented the intervention and in what setting

Limitations

- Read through to learn what the researchers say are the weaknesses of the study so you can balance those with the study's strengths

Conclusion

In general, be skeptical when evaluating research. Don't be afraid to assess the merit of a study based on your own common sense. Always bear in mind that you are your child's most important advocate, and if you have any misgivings and questions about a given study, remember that there are many knowledgeable parents and professionals in the autism community with whom you can discuss your concerns.

Scientific progress occurs slowly over time. It is not represented by a single study, but by a large body of research. Each study builds on prior studies. New theoretical frameworks, methods, and statistical analyses are developed. Over time, typically decades, the findings converge on points of agreement. Researchers collect and analyze findings from across a large body of research and summarize them in **meta-analyses** or **systematic reviews**. Meta-analyses and systemic reviews aim to synthesize relevant studies on a particular topic in an unbiased manner.

Read as much as you can on a particular research topic in order to form your own educated opinion. In the final analysis, it is ultimately up to you to decide if a particular study makes sense for your child, or has what researchers refer to as **face validity**. As a parent, you are the expert on your child. If something does not "ring true" to you, trust your instincts, confer with others, and make your own educated assessment.

Glossary of Research Terms

Baseline: A benchmark that measures the usual participant condition or performance.

Bias: A condition that, if not controlled, can influence the results of a research study.

Blind: Participants are "blind" when they do not know whether or not they are receiving the treatment or intervention being used in a research study.

> **Double blind**: A "double-blind" condition exists when neither the participant nor the researcher knows which participants are receiving the treatment or intervention being used in a research study.

Case: A "case" refers to one group under observation in a study, or one instance of something occurring.

> **Multiple cases**: "Multiple cases" refers to more than one group or one instance of something occurring.

Cohort: A group of individuals identified by a common characteristic that is studied over a period of time as part of a scientific investigation.

Control: The condition or group in a research study that does not receive treatment.

Cross-section: A group of people who differ in age and/or other factors who provide information for the research study at the same point in time.

Evidence-based: An approach to healthcare, education, and other disciplines that emphasizes applying to practice and implementation of treatments/interventions the cumulative findings of current, high-quality research that demonstrated evidence of effectiveness.

Face validity: A study is said to have "face validity" if it "rings true," or makes sense.

Generalized: The reasoning by which a researcher is able to conclude with a certain degree of confidence that the findings of a study can be applied to other persons or situations.

Instrument and measure: These two terms are used interchangeably to denote tools used to assess the outcome of a study, such as a questionnaire or an observational coding scale.

Intervention: A treatment or program that is designed to change the targeted behavior, perception, or condition of the participants.

Manipulation: Occurs in an experiment, when a researcher does something to one variable to see if it affects another variable.

Mean: The average score for a group of participants.

Meta-analysis: A statistical analysis of findings from multiple research studies.

Participant expectations: Results that people expect to happen when they participate in a research study.

Peer review: Articles submitted to academic and scientific journals are generally reviewed by a committee of peers (other researchers in the field) for scientific merit and accuracy before appearing in a journal.

Placebo: A pretend treatment that participants believe is the real treatment, such as a sugar pill.

Random assignment: A method similar to “flipping a coin” used to assign participants in a study to be in either an experimental or a control group so that they have an equal chance of being in either group.

Reliable: In research, something is considered to be reliable if it produces similar results when tested at different times.

Research-based: Interventions or practices that have theory-based foundations, but do not have cumulative evidence of effectiveness from multiple independent, rigorous research studies.

Researcher expectations: Results that researchers expect to happen when they conduct a research study.

Self-selected: Participants in research are considered “self-selecting” when they volunteer to participate in a study.

Statistically significant: The results of a study are considered “statistically significant” when the probability that they are due to chance is less than 5%.

Subject: Someone who participates in a study.

Systemic review: A detailed, unbiased synthesis of related research studies that answer a well-defined research question.

Validity: In research, the quality of being factually sound—that something is what it is supposed to be, and not something that it should not be.

Variables: The thing or things that are being studied.

Autism Resources

Many autism and disability organizations exist across the country, from small local support groups to broad-based, federally funded organizations. Below is a partial list of resources that promote autism research and provide family resources. These include autism organizations that fund research, list opportunities for families to participate in research, or provide useful information about current research trends and activities. Several of these websites also offer practical information to support families living with autism, such as information tool kits, guidebooks, grants, scholarship opportunities, and more.

Autism Science Foundation (ASF; New York, NY)
https://autismsciencefoundation.org/
Autism Science Foundation is a non-profit organization that lists research participation opportunities for families and offers research funding opportunities for researchers.

Autism Society of America (Bethesda, MD)
http://www.autism-society.org
Autism Society of America is a national advocacy and membership organization with numerous local chapters across the country.

Autism Speaks (New York, NY)
https://www.autismspeaks.org/
The Autism Speaks website lists resources to meet the needs of individuals with ASD and their families, educators, healthcare professionals, and employers across the lifespan. It also lists research participation opportunities and offers research funding opportunities for scientific researchers.

Centers for Disease Control and Prevention (CDC)
https://www.cdc.gov/ncbddd/autism/index.html
The CDC is dedicated to better understanding ASD as it relates to public health in the United States. They collect and provide up-to-date data on factors, causes, and prevalence rates of ASD.
https://www.cdc.gov/ncbddd/actearly/index.html
The CDC has a "Learn the Signs. Act Early." program that aims to improve awareness and early identification of autism and other developmental disabilities. The website includes videos, caregiver resources, case training and awareness resources, and epidemiological study results.

Interagency Autism Coordinating Committee (IACC; Rockville, MD)
https://iacc.hhs.gov
IACC is a federal advisory committee that was first established under the Children's Health Care Act of 2000. The IACC coordinates public and private research efforts conducted in the U.S.; serves to guide federal agencies in setting research, program, and funding priorities by delivering annual updates on autism research trends and advances; and publishes up-to-date reports on the latest research breakthroughs for public consumption.

Institute for Education Sciences (IES)
https://ies.ed.gov/ncser/projects/program.asp?ProgID=42
IES is a national research center in the that funds school-based studies aimed at improving student outcomes from preschool through 12th grade. A branch of IES, the National Center for Special Education Research (NCSER), funds studies related to ASD. The IES website lists all previous and currently funded IES/NCSER studies. The site also includes links to briefs summarizing study findings. Full-text articles from IES-funded studies are required to be posted on ERIC: www.eric.ed.gov.

National Institutes of Health (NIH; Bethesda, MD)
https://www.nichd.nih.gov/health/topics/autism
NIH is one of the world's leading research centers. Several institutes within NIH fund studies related to autism, including the National Institute of Mental Health (NIMH), National Institute on Deafness and Communication Disorders (NIDCD), National Institute of Environmental Health Sciences (NIEHS), National Institute of Neurological Disorders and Stroke (NINDS), and National Institute for Child Health and Human Development (NICHD). NICHD lists clinical research projects, publications, news releases, and other activities related to autism and similar disorders.

Organization for Autism Research (OAR; Arlington, VA)
http://www.researchautism.org
OAR is a non-profit organization that offers research grant opportunities for scientific researchers and graduate students. OAR also provides information resources for caregivers, professionals, and individuals with autism, such as teacher training videos, peer education tools, and siblings guidebooks. OAR also grants scholarships for individuals with autism seeking postsecondary education.

Simons Foundation Autism Research Initiative (SFARI; New York, NY)
https://www.sfari.org
SFARI funds scientific research in autism such as genetics and biological mechanisms investigations. It also provides resources to researchers, including tools, data, and stem cell lines.

Recommended Readings

Below is a sampling of books, research reports, and research journals available to help you understand autism and research. This list is meant to be used as a starting point in your reading. When you read these books, you will find additional resources cited in them. Many of these books will serve as valuable references to you as you continue to learn about your child's diagnosis.

Books on Autism

Bernier, R., & Gerdts, J. (2010). *Autism spectrum disorders: A reference handbook.* Santa Barbara, CA: Contemporary World Issues.

Matson, J. (Ed.). (2016). *Handbook of assessment and diagnosis of autism spectrum disorder.* New York, NY: Springer International Publishing.

Matson, J. (Ed.). (2017). *Handbook of treatments for autism spectrum disorder*. New York, NY: Springer International Publishing.

Ozonoff, S., Dawson, G., & McPartland, J. (2015). *A parent's guide to high-functioning autism spectrum disorder, second edition: How to meet the challenges and help your child thrive.* New York, NY: Guilford Press.

Prelock, P., & McCauley, R. (2012). *Treatment of autism spectrum disorders: Evidence-based intervention strategies for communication and social interactions*. Baltimore, MD: Paul H. Brookes Publishing Co.

Rieske, R. (Ed.). (2019). *Handbook of interdisciplinary treatments for autism spectrum disorder.* New York, NY: Springer International Publishing.

Rosenblatt, R., & Carbone, P. (Eds.). (2013). *Autism spectrum disorders: What every parent needs to know.* Elk Grove Village, IL: American Academy of Pediatrics.

Books on Reading and Interpreting the Research

Girden, E. R. (2001). *Evaluating research articles from start to finish*. Thousand Oaks, CA: Sage Publications.

Locke, L., Silverman, S., & Spirduso, W. (2010). *Reading and understanding research, third edition.* Thousand Oaks, CA: Sage Publications.

Webster, A., Cumming, J., & Rowland, S. (2017). *Empowering parents of children with autism spectrum disorder: critical decision-making for quality outcomes.* Singapore: Springer.

Research Journals

Autism. *Autism* is a peer-reviewed, international journal published eight times a year by SAGE Publications. It features studies that have direct and practical relevance for helping to improve the quality of life for individuals with autism or autism-related disorders, such as intervention, diagnosis, training, education, and more.

Journal of the American Academy of Child and Adolescent Psychiatry. Published by Elsevier, this research journal features articles from diverse viewpoints including genetic, neurobiological, cognitive, behavioral, and psychodynamic investigations. The journal seeks to promote the wellbeing of children and families by publishing scholarly papers on such subjects as health policy, legislation, advocacy, culture, and service provision as they pertain to the mental health of children and families.

Journal of Autism and Developmental Disorders (JADD). Published by Springer Science+Business Media, the *Journal of Autism and Developmental Disorders* is a leading peer-reviewed scholarly periodical focusing on all aspects of ASD and related developmental disabilities. JADD covers potential causes and prevalence, effective clinical care, education, and treatment for all individuals.

Pediatrics. *Pediatrics* is an official peer-reviewed journal of the American Academy of Pediatrics (AAP). *Pediatrics* publishes original research, clinical observations, and special feature articles in the field of pediatrics.

Research Summaries and Reports on Autism

Autism Speaks. (2017). *Autism and health: Advances in understanding and treating the health conditions that frequently accompany autism*. Retrieved from https://www.autismspeaks.org/sites/default/files/2018-09/autism-and-health-report.pdf

Interagency Autism Coordinating Committee (IACC). (2017, October). *2016-2017 interagency autism coordinating committee strategic plan for autism spectrum disorder*. Retrieved from https://iacc.hhs.gov/publications/strategic-plan/2017/.

Interagency Autism Coordinating Committee (IACC). (2019, April). *2018 IACC summary of advances in autism spectrum disorder research*. Retrieved from https://iacc.hhs.gov/publications/summary-of-advances/2018/.

Roux, A. M., Rast, J. E., Anderson, K. A., & Shattuck, P. T. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood*. Philadelphia, PA: Drexel University, A. J. Drexel Autism Institute, Life Course Outcomes Program.

Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood.* Philadelphia, PA: Drexel University, A. J. Drexel Autism Institute, Life Course Outcomes Research Program.

Sussman, A. (2015). *Summary of autism spectrum disorders research* [PDF]. National Center for Special Education Research (NCSER). Retrieved from https://ies.ed.gov/ncser/pdf/ASD_2015.pdf

Wong, C., Odom, S., Hume, K., Cox, A., Fettig, A., Kucharczyk, S., …Schultz, T. (2014). *Evidence-based practices for children, youth, and young adults with autism spectrum disorder*. Chapel Hill, NC: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.

APPENDICES

Appendix A: Current State of Autism Research

This appendix provides a brief overview of the current state of autism research on key topics across the lifespan, drawn from research summaries and reports published between 2015-2018. The appendix is not meant to be comprehensive, and does not capture the complete range of topics nor breadth of each topic. Further information may be found under Recommended Readings on page 39.

Causes of Autism

Everyone inherits certain traits from their parents. Genes are the biological mechanism through which we inherit these traits. At the same time, environmental factors may influence how these biological traits are expressed. This complex interplay between our genes and our environment is known among researchers as the "nature versus nurture debate." We have begun to make technological advances in the 21st century that allow us to conduct sophisticated genetic research studies. For example, researchers have conducted studies that will help us understand the complex interplay between genes and the environment in determining the symptoms of autism. Knowing the specific underlying causes of autism may ultimately allow interventions to be targeted specifically to individuals with certain genetic or biological traits.

Some parents suspect the MMR (measles, mumps, and rubella) vaccine causes the onset of autism. This is likely due to the fact that their first awareness of symptoms is in the second year of life when signs of autism (e.g. significant regression of social behaviors) typically emerge—around the same time children receive the vaccine. However, studies have failed to show a causal link between vaccines and autism. In fact, studies have demonstrated the absence of such a causal relationship. In addition, there is considerable evidence that there are differences in brain development that lead to autism prior to birth.

Early Diagnosis

Recent studies have shown that screening tools can be used to detect early indicators of autism in infants as young as 12-18 months of age; yet, the majority of children continue to remain undiagnosed until 3-4 years of age if not longer. Several factors contribute to this delay, including clinicians having limited understanding of the early manifestations of autism, lack of universal screening of toddlers for autism, and lack of resources. To help prevent, or shorten, this critical delay, national initiatives have been launched, such as the Centers for Disease Control and Prevention's (CDC) "Learn the Signs. Act Early." Program, designed to promote awareness about the early signs of autism with the goal of enrolling children in intervention as early as possible.

Early Intervention

Closely related to early diagnosis is early intervention. Prompt educational intervention is key to helping children with autism learn the skills needed for self-care, school success, and community functioning. Research suggests that early intervention is critical to improving the quality of life and long-term outcomes for children with autism.

In the past, early intervention studies were generally conducted in clinical settings. However, now there is substantial research evidence supporting more "naturalistic" behavioral interventions that are applied in home or school settings within a child's daily routines. That is, instead of therapists implementing interventions, research supports coaching parents to implement intervention strategies so that children can receive support throughout the week instead of just during therapy sessions. As a result, early intervention studies are now being conducted with infants and toddlers.

Educating Children With Autism

Children with autism are educated in a variety of educational environments ranging from specialized schools and classrooms to full integration with their neurotypical peers. Integrated settings offer many social and educational advantages for children with autism; however, careful instructional planning is critical to ensure success among all students in the inclusive classroom. To that end, studies are being conducted in classrooms to evaluate the effectiveness of programs that aim to improve academic, social, behavioral, communication, and executive functioning skills of students with autism across a variety of educational settings. In 2015, the National Center for Special Education Research (NCSER) published a comprehensive summary of autism research that includes an overview of the ongoing and complete research studies to date.

The Report from the National Center for Special Education Research on educating children with autism may be found at: https://ies.ed.gov/ncser/projects/research_summaries.asp.

With a look toward the future, all students with autism are required to have a transition plan built into their individualized education program (IEP) starting in middle and high school. A well-developed and implemented transition plan is critical to ensuring children are prepared to live and work independently beyond high school.

Many transition, postsecondary, and vocational programs have surfaced to help individuals with autism and other disabilities adapt to and succeed in higher education settings. Further research is needed to examine the characteristics and effectiveness of these programs in community colleges and universities, and to help guide program developers, service providers, and policymakers.

Demographic Factors

There are many demographic factors to consider, such as race, ethnicity, socioeconomic status, geographic region, parent education, and sex. Studies in autism were previously limited by small samples restricted to a certain geographic area and participation of primarily middle- to high-income white families. Now, multisite studies and national research registries allow researchers to examine group differences in large and diverse samples. Looking at differences in how effective an intervention is based on these demographic factors can have significant implications for determining which interventions best serve a given individual.

Health and Safety

Individuals with autism have greater physical health and safety concerns than the general population, ranging from obesity and gastrointestinal issues to self-harm and being victims of sexual assault. They also experience greater mental health challenges. For example, more than half of adults with autism have a co-occurring psychiatric condition—often a mood or anxiety disorder. Further, individuals with autism are at high risk of engaging in suicidal thoughts and behaviors. Little information is available on the topic of suicidality, and researchers have only begun to investigate the issue.

Employment

Adults with autism experience high rates of unemployment; indeed, even those who complete college and receive vocational rehabilitation services are under- or unemployed. With the appropriate training and support, persons with autism can and should be employed. To this end, research is needed regarding issues such as how best to assess "job match," how to best identify and address barriers to meaningful employment, what employer variables are associated with more positive employment outcomes, and to what extent coworker training is integral to success in workplace settings for individuals with autism.

Adult Support Services and Housing

Autism is a lifelong disorder. However, although the symptoms of autism do not end when children reach adulthood, many federally mandated transition and support services do, leading to what many parents describe as seeing their children "fall off a services cliff." For example, studies consistently show that adults with autism experience social isolation and difficulty accessing disability services. As a result, there has been an increased research emphasis on determining the most effective ways to prepare students for their transition from school to adult services.

Most individuals with autism require some degree of support throughout their lives. The intensity of such care will vary from person to person: It may range from 24-hour supervision to monthly case management. In general, families often play the essential role of providing caregiver supports across the lifespan.

To date, little systematic research has been published on the types of housing options available for adults with autism. Some argue that community-based housing leads to increased community participation and independence and, therefore, is preferable to so-called intentional communities or larger care settings. However, to date, there is limited data to indicate which housing options work best for individuals with autism. Further research is needed to determine the best housing fit and the factors that lead to increased community engagement and overall quality of life for adults with autism.

Technology

The past several decades have witnessed an exponential growth in new technologies. Some of these advanced tools may be used to better understand and support individuals with autism. For example, researchers use affordable, GPS-enabled fitness watches to measure, monitor, and understand health and behavior related to physical activity, sleep, travel, and community engagement. For-profit businesses are teaming up with researchers to develop and market commercially viable technological products for individuals with autism. These range from online education training programs to apps that use computer vision analysis for early autism detection and monitoring. Especially given the speed with which new technologies emerge, it is important to conduct research that systematically reviews and determines the efficacy of these varied technologies.

Individual Quality-of-Life Assessment

Only in the past decade or so have autism researchers and practitioners begun to actively address the issue of quality of life for adolescents and adults with autism. However, as increasing numbers of individuals with autism are receiving community-based services in adulthood, questions regarding how best to define, assess, implement, and measure individual quality of life have become increasingly relevant. As quality-of-life issues are becoming more prominent, well-designed research into this particular area is becoming more critical.

Conclusion

Research helps us understand autism and how to best support the needs of individuals and families affected by autism. Despite progress in recent years, many unanswered questions and issues remain that require further investigation. It is our hope that this guide will provide you the tools needed to explore and evaluate research to promote optimal outcomes for your child.

Appendix B:
Participating in Research Studies

Appendix B: Participating in Research Studies

Researchers actively recruit children with autism as participants. Participation is always voluntary. The decision to participate in a study is a personal one. If you decide that you would like your child to participate, some important points should be considered. This appendix lists research registries offering opportunities to participate in research, and a list of questions and answers about participating in research studies.

Research Registries and Opportunities to Participate in Research

For Clinical Trials

- Interagency Autism Coordinating Committee (U.S. Department of Health & Human Services), *Community Participation Opportunities*: https://iacc.hhs.gov/resources/community-participation/
- National Institute of Child Health and Human Development (NICHD), *Find a Study on Autism*: https://www.nichd.nih.gov/health/topics/autism/clinicaltrials
- National Institutes of Health (NIH), *Clinical Research Trials and You*. This site is a resource for people who want to learn more about, and potentially participate in, clinical trials across a variety of health topics; it includes a list of registries: https://www.nih.gov/health-information/nih-clinical-research-trials-you.
- National Institutes of Health (NIH), U.S. National Library of Medicine, ClinicalTrials.gov, searchable database of privately and publicly funded clinical studies: https://clinicaltrials.gov/ct2/home

University-Affiliated Autism Research Registries

Large research universities that have departments or centers studying autism maintain a registry or listing of current studies open to families interested in participating in research. Here are some examples:

- Duke Center for Autism and Brain Development: https://autismcenter.duke.edu/research/registry-autism-research
- Kennedy Krieger Institute: https://www.kennedykrieger.org/research/participate-in-research

- Marcus Autism Center: http://www.marcus.org/Research/Available-Research-Studies
- Stanford University: https://med.stanford.edu/autism/registry.html
- Thompson Center for Autism & Neurodevelopmental Disorders: https://thompsoncenter.missouri.edu/
- UC Davis MIND Institute: https://health.ucdavis.edu/mindinstitute/research/index.html
- UNC Carolina Institute for Developmental Disabilities: http://www.cidd.unc.edu/registry/autism/
- Vanderbilt Kennedy Center: https://vkc.mc.vanderbilt.edu/vkc/

Questions and Answers About Participating in Research Studies

Q. Will I learn more about my child from participating in a study?

A. Be sure you understand the purpose of a study. Generally, research studies are conducted to collect group data, so you will probably not receive any information specific to your child as an individual.

Q. How can I be sure that it is safe for my child to participate in a study?

A. Inquire about the ethical review process that the study had to undergo before it was approved to be conducted. Be sure that the research is being carried out in a controlled environment that is committed to the protection of participants' rights. Generally, studies conducted at universities and medical institutions must receive prior approval from institutional review boards, whose job it is to make sure that the research is ethical and safe. Private facilities are not always as closely regulated, so be sure to inquire about their systems of review and safeguards, if relevant. In addition, you should also inquire about what tests, medications, or procedures are involved for your child and other family members.

Q. How can I be sure that the study will not demand too much of my time?

A. Be sure you understand the requirements of participation. Find out how long the study is expected to last and how much time you will have to commit: Will you have to participate on a daily or weekly basis? How many hours per day are required?, etc.

Q. If the study is using a randomized control design, how will I know if my child is in the control or the treatment group?

A. Remember the discussion about randomized experimental studies in the section on Understanding the Scientific Model (see page 18)? Your child has a 50/50 chance of being assigned to either a treatment or a placebo group, and you will not be told of your child's group assignment until the conclusion of the study. For this reason, it is very important to fully understand whether or not your child will have an opportunity to receive the treatment at the conclusion of the study if your child was assigned to receive the placebo. Sometimes, researchers use a so-called "cross-over" design, in which groups switch conditions after a period of time. If this is the case, your child will be assured to receive the intervention. However, to keep you and your child "blind" to your group assignment, you will not always know that the research is using a cross-over design in advance of the study.

Ethical Considerations in Research Involving Human Participants

The American Medical Association and the American Psychological Association have strict codes of ethics that all researchers must follow when conducting research involving human participants. As a participant, you should be informed about all aspects of the research, including:

- *Potential risks of participation*: You should be informed of any potential risks to you or your child as a consequence of participating in a study.
- *Benefits of participation*: You should be informed of the benefits of participation.
- *Assurance of confidentiality*: You should be informed of how researchers will ensure the confidentiality of you and your child's personally identifiable information.
- *The right to withdraw from the research at any time*: Your participation is voluntary, and you have the right to withdraw from the study at any time with no penalty.
- *Informed consent*: Researchers must obtain your written informed consent for participation.

> If you are not informed of all of these aspects of
> the research, do not participate in the study.

Appendix C:
Sample Research Articles

The following sample research articles are fictional and used for illustrative purposes only. They include a case study, correlational study, longitudinal study, experimental study, and clinical trials study that were defined in the "Understanding the Scientific Model" chapter.

Sample Case Study

Journal of Collaborative Autism Research (2017), *1*(2), 222-223.

name of journal ***year of publication*** ***volume*** ***issue*** ***page numbers of article***

Sleep Patterns in a Child With Autism ← ***title of article***

Jane Doe ← ***name of author***

Academic University, Anytown, USA ← ***university or organization***

Abstract

This study reports on the sleep patterns of a boy with autism over the course of his fifth year of life. A one-year diary revealed seasonal changes in sleep patterns. The results are discussed in terms of their application to future research.

Introduction

previous research cited

Parents often report sleep problems in children with autism (Callahan, 2016; Rogers & Brown, 2016). Moreover, research reveals that problems in sleep may be affected by seasonal changes (Robins, Williams, Jones, & Miller, 2015). However, to date there have been no studies investigating the relationship between seasonal changes and sleep patterns in children with autism. [*Therefore, the purpose of the present study was to examine whether the sleep patterns of a child with autism were affected by seasonal changes*.]

previous research cited

Often a research question will be expressed in the form of a statement on the purpose of the study.

Method

The subject was a male with autism. His mother kept a diary of his sleep habits over the course of his fifth year of life, beginning on his fourth birthday and ending on his fifth birthday. Based on daily entries made in the diary, a trained researcher noted days indicating sleep problems (such as restlessness or wakefulness).

Results

A total score was calculated for incidents of sleep problems. [*For each month, a score for sleep problems was determined by calculating the number of days in each month when these problems were recorded and summing the number across the three months for each season*.]

Case studies often report only descriptive results with no statistical data.

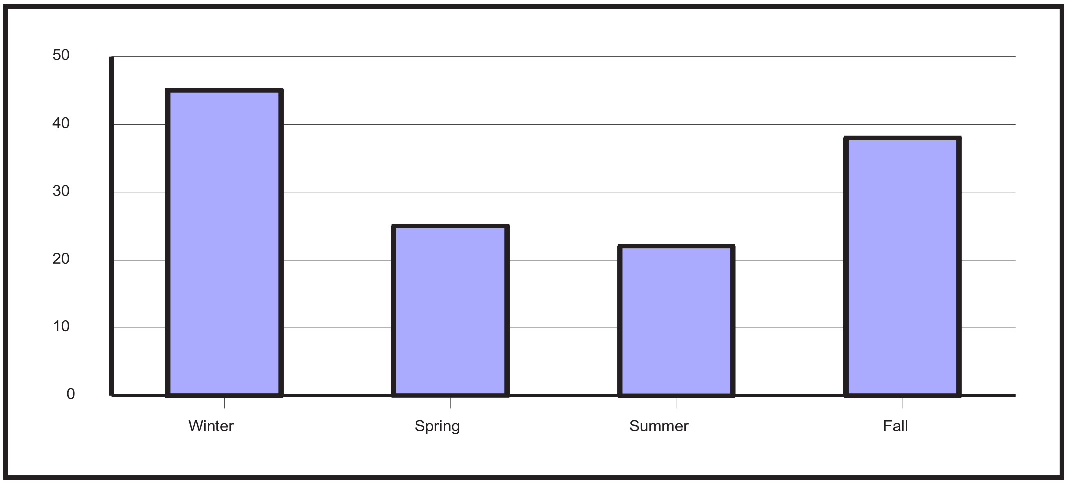
The sleep problem scores for each of the three month seasons are presented in Table 1.

Table 1. Seasonal Sleep Problem Scores

	Winter	Spring	Summer	Fall
Mean Score:	45	25	22	38

As shown in both Table 1 and Figure 1, sleep problems increased in the fall and winter and decreased in the spring and summer.

Figure 1. Seasonal pattern of sleep.



Discussion

Author's interpretation of the findings of the study.

This study reported on a seasonal pattern of sleep problems in a boy with autism during his fifth year of life. Specifically, the study found that disturbances in sleep problems occurred at higher frequencies in the winter and spring, and diminished during the summer and fall. [*It may be that seasonal changes in light cause these disturbances. In this study, sleep problems occurred during the seasons when the days are shortest and there is the least daylight in the northern hemisphere*.] In support of this assumption, previous research has found an increase in disturbances in behavior in children with developmental disabilities during the winter and fall (Marks, Cohen, & Winthrop, 2017; Price, 2015). [*Thus, future research is needed to determine if this seasonal pattern in sleep disturbance is found in other children with autism*.]

previous research cited

Author suggests direction for future research.

Sample Correlational Study

Journal of Family Research (2019), *21*(4), 1223-1245.

name of journal ***year of publication*** ***volume*** ***issue*** ***page numbers of article***

"Like Father Like Son:" The Relationship Between Fathers
in Scientific Professions and Sons With Autism ← ***title of article***

Thomas Ward, Mary Wainwright, and Margaret Meyers ← ***name of author***

Middletown University, Anytown, USA ← ***university or organization***

Abstract

The purpose of the present study was to determine if there was a relationship between boys diagnosed with autism and having fathers in scientific professions. Surveys were sent to fathers in scientific professions and fathers in nonscientific professions to ascertain the number in each group who reported having a son diagnosed with autism. Results revealed that fathers in scientific professions were significantly more likely to have sons diagnosed with autism than fathers in nonscientific professions. The findings of the study are discussed in terms of their implications for future research.

Introduction

previous research cited

It is well established that significantly more boys are diagnosed with autism than girls, with ratios consistently reported at four boys to every one girl (Billings, Dweck, Klinger, & Newman, 2018). There is less evidence that the transmission of the disorder follows the path from father to son. While anecdotal reports have suggested higher rates of certain "scientific" traits and tendencies in fathers of boys diagnosed with autism than in fathers of typical boys (Phillips, 2019; Ziegler, 2015), to date, no research studies have been conducted to determine if certain traits in fathers are associated with having a son diagnosed with autism. [*The present study sought to determine if fathers in scientific professions were more likely to have sons diagnosed with autism than fathers in nonscientific professions*.]

previous research cited

Research Question

Method

Subjects

The subjects were 498 men in scientific professions (75% Caucasian, 10% African American, 15% Asian) and 658 men in nonscientific professions (60% Caucasian, 15% African American, 10% Asian, and 15% Hispanic). Subjects in both groups were between the ages of 22 and 65; mean age was 42 and 38, respectively.

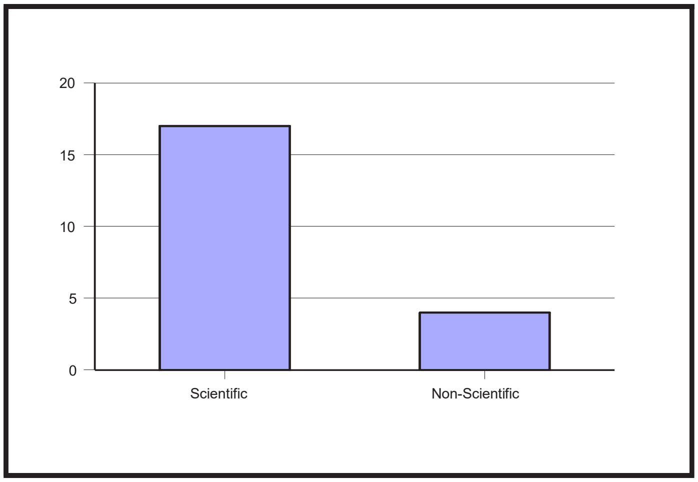
Procedure

Surveys were mailed to the homes of 2,000 men selected at random from scientific corporations and 2,000 men randomly selected from nonscientific organizations. Postage-paid, return envelopes were included with the surveys to encourage their return. The surveys were designed to collect basic demographic data (e.g., age, profession, education) as well as "family information." Several questions were asked about the subjects' family members, including a question that asked: "Have any of your children been diagnosed with any of the following disorders: autism, cerebral palsy, spina bifida." Respondents were asked to give the age and gender of the child diagnosed with a disorder, if applicable. A total of 498 men in scientific professions and 658 men in nonscientific professions returned completed surveys.

Results

Percentage scores were calculated for both groups. As shown in Figure 1, the percentage of men in scientific professions with sons diagnosed with autism was significantly higher than the percentage of men in nonscientific professions.

Figure 1. Percentage of men with sons diagnosed with autism in scientific and nonscientific professions.



Discussion

The present study sought to determine if fathers in scientific professions were more likely to have sons diagnosed with autism than fathers in nonscientific professions. The results of a survey sent to a random sample of men in scientific and nonscientific professions revealed a significant between-group difference in the percentage of fathers with sons diagnosed with autism.

The results of this study lend support to anecdotal reports of higher rates of certain "scientific" traits and tendencies in fathers of boys diagnosed with autism than in fathers of typical boys (Phillips, 2019; Ziegler, 2015). However, although the results of this study were significant, they only show a relationship between paternal "scientific" characteristics and sons with autism. Future research is needed to provide more sound scientific evidence of this relationship.

Sample Longitudinal Study

Journal of Longitudinal Autism Research (2018), *4*(5), 138-145.

name of journal ***year of publication*** ***volume*** ***issue*** ***page numbers of article***

A One-Year Followup of Children With Possible Autism ← ***title of article***

Scarlet Mitchel ← ***name of author***

The Institute for Autism Research and Education, Anytown, USA ***university or organization***

Abstract

Twenty-five children between the ages of 18 months and 3 years were referred to a diagnostic clinic for suspected autism spectrum disorder (ASD). They were evaluated for ASD using a standardized parent interview (Smith, 1995) and the Behavioral Rating Scales (Jones & Harper, 1989). The children who received a clinical diagnosis of ASD were re-evaluated one year later to determine if they still met the diagnostic criteria of ASD. Results revealed that diagnosis of ASD remained stable over time.

Introduction

previous research cited

Recently, there has been a movement towards early diagnosis of autism spectrum disorder (ASD) (Aaron, King, & Farquire, 2015). Because several scientists have determined that early intervention offers a greater chance to intervene, it is generally believed that the earlier the diagnosis of autism, the better the opportunity for early intervention (Blackman, 2015; Carlson, 2016; Rogers & Hammerstein, 2015). However, some child development specialists fear that a diagnosis of autism made before the age of 3 years old may be premature and that children diagnosed before the age of 3 may not meet the same diagnostic criteria after age 3 (Howell, Musselman, Treman et al., 2017). [*The purpose of the present study was to determine if children who received a clinical diagnosis of ASD before their third birthday would still meet the diagnostic criteria of the disorder one year later*.]

previous research cited

Research Question

Method

Subjects

The subjects were 20 males and 5 females between the ages of 18 months and 3 years, who were referred to a diagnostic clinic for suspected ASD. The 20 males consisted of 15 Caucasian, 3 African American, and 2 Asian children. The 5 females consisted of 3 African American and 2 Caucasian children.

Procedure

The subjects were evaluated for ASD using a standardized parent interview (Smith, 2015) and the Behavioral Rating Scales (Jones & Harper, 2018) at two points in time. All the subjects were evaluated at the time of initial intake (Time 1). The children who received a clinical diagnosis of ASD were re-evaluated one year later (Time 2) to determine if they still met the diagnostic criteria of ASD. Evaluations were conducted by independent clinicians at Time 1 and Time 2 to control for experimenter bias.

Results

Inter-rater reliability between clinical assessments at Time 1 and Time 2 was assessed using Chronbach alpha correlation coefficients. Independent assessments using the parent interview and the results of the Behavioral Rating Scales demonstrated high rates of internal consistency, with mean scores on both instruments ranging between .65 and .97. See Table 1 for mean scores on the two subscales of the parent interview (Social Interaction and Communication) and the Behavioral Rating Scales.

Table 1. Interrater Reliabilities for the Three Subscales of the Parent Interview

Scale	Minimum	Maximum	Mean
Social Interactions	.80	.97	.89
Communication	.72	.95	.84
Behavioral Rating Scales	.65	.88	.77

Discussion

The present study sought to determine if children who received a diagnosis of ASD before their third birthday would still meet the diagnostic criteria of the disorder one year later. The results of the study lend strong support to the argument for early diagnosis of ASD (Blackman, 2015; Carlson, 2016; Rogers & Hammerstein, 2015). Thus, the independent assessments by clinicians conducted when the children were under the age of 3 and one year later were highly consistent. [*Thus, based on the results of this study, we would advocate for early diagnosis of ASD*.]

Author's conclusions based
on the findings of the study.

Sample Experimental Study

Journal of Autism Intervention Studies (2019), *6*(1), 567-575.

name of journal ***year of publication*** ***volume*** ***issue*** ***page numbers of article***

The Effects of an Intervention Targeting Negative
Behavior in Preschool Children With Autism ← ***title of article***

Yolanda Jones and Sarah Winston ← ***name of author***

Research Analysts Incorporated, Anytown, USA ← ***university or organization***

Abstract

An intervention targeting negative behavior in preschool children with autism was tested in four preschools for children with developmental disabilities in a large city in the midwestern United States. Schools were randomly assigned to receive either the intervention or a control condition. Results revealed that children in the intervention schools demonstrated a significant decrease in both intensity and frequency of negative behaviors following the intervention; negative behaviors in children in the control condition did not change from baseline to posttest. The study demonstrates the effectiveness of an intervention designed to reduce negative behavior in preschool children with autism.

Introduction

previous research cited

Interventions designed to correct negative behavior in children with autism are typically designed to be delivered on an individual basis (e.g., applied behavioral analysis). While many attest to the efficacy of interventions targeting individuals, it seems more time- and cost-efficient to design interventions that could be conducted with groups of children with autism. A review of the literature found several studies designed to target groups (Jenkins & Howell, 2019; Miller, 2015). ← The results of these studies were mixed. While Jenkins and Howell (2019) found some benefits, the Miller (2015) study failed to show a significant difference between children who received the intervention and children in the control group.

The purpose of the present study was to test the efficacy of an intervention designed to reduce the negative behavior of children with autism in a preschool setting. [*It was predicted that, compared with the control group, children who received the intervention would demonstrate a significant decrease in negative behavior following intervention*.]

Specific hypothesis

Method

Subjects

The subjects were 38 children with autism between the ages of 3 and 5 years old. There were 32 boys and 6 girls—31 Caucasian, 4 African American, 1 Asian, and 2 Hispanic.

Procedure

Four schools were randomly assigned to receive either the intervention or no intervention; two schools were assigned to the experimental group and two schools were assigned to the control group. The experimental group included 22 children, and the control group included 16 children. The intervention consisted of group exercises in correcting negative behavior, conducted every day for three weeks. The control group received no exercises ("business-as-usual").

Research assistants were trained to make observational assessments of negative behavior. Baseline observational measures of negative behavior were recorded prior to the intervention for the experimental group and on the same day for the control group. These same measures were recorded for the experimental group at a one-week post-intervention followup assessment and on the same day for the control group. Research assistants were blind to the children's group assignments.

Results

Statistically significant findings

Paired-sample t-tests revealed a significant difference between groups in both frequency ($t = 2.935$, $p < .05$) and intensity ($t = 1.556$, $p < .05$) of negative behavior on the posttest. Table 1 presents the means and standard deviations for the two groups.

Table 1. Means and Standard Deviations in Frequency and Intensity of Negative Behavior at Time 2

Scale	Pretest	Posttest
Frequency of Negative Behavior		
Experimental Group	39 (14)	27 (9.7)*
Control Group	35 (16)	36 (15)
Intensity of Negative Behavior		
Experimental Group	41 (12)	30 (11)*
Control Group	42 (7.8)	40 (8.6)

*$p < .05$.

Discussion

The purpose of the present study was to test the efficacy of an intervention designed to reduce the negative behavior of children with autism in a group setting. It was predicted that, compared with the control group, children who received the intervention would demonstrate a significant decrease in negative behavior following intervention. Results of the study supported the hypothesis; compared with a control group, children significantly reduced both the frequency and intensity of negative behavior following intervention. [*These results indicate that interventions that target children with autism at the group level can be a very effective means of changing behavior. Future research is needed to determine if the effects of the intervention hold up over time.*]

Author's conclusions based on the findings of the study.

Sample Clinical Trials Study

Journal of Clinical Trial Studies in Autism (2019), 9(5), 894-912.

name of journal ***year of publication*** ***volume*** ***issue*** ***page numbers of article***

The Effects of a New Drug for the Treatment of Autism ← ***title of article***

Marshall Grand ← ***name of author***

National Institute of Health Research, Anytown, USA ← ***university or organization***

Abstract

A new drug for treating autism was tested in a double-blind controlled design with a group of children with autism. Although more children in the experimental group demonstrated improvement in their symptoms than the children taking a placebo, the differences were not significant. Future research is needed to further investigate the effects of this drug.

Introduction

Many psychotropic drugs have been tested for their efficacy in treating the symptoms of autism (e.g., Tucker, Jones, & Martin, 2019; Vanelli, 2018). However, to date, none has proven to be effective for the majority of children with autism. The purpose of the present study was to test the efficacy of a new drug for treating the symptoms of autism. [*It was predicted that, compared with children who received a placebo, children who received the new drug would demonstrate significant improvements in their symptoms of autism*.]

Specific hypothesis

Method

Subjects

The subjects were 24 children with autism between the ages of 5 and 8 years old. There were 21 boys and 3 girls of mixed racial background.

Procedure

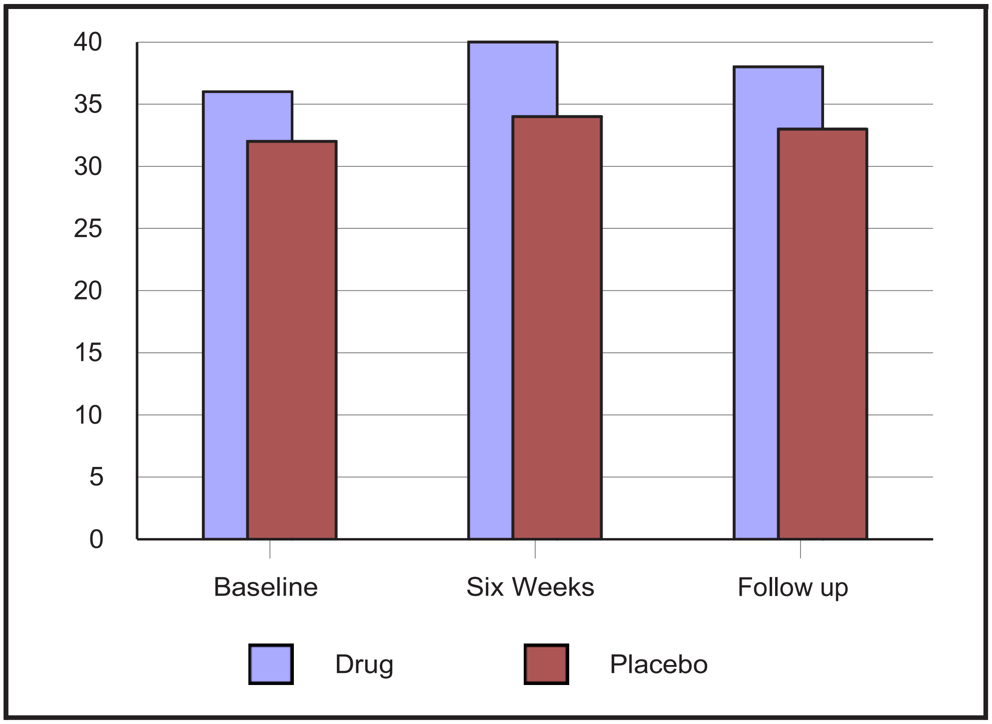
Children were randomly assigned to receive the new drug or a placebo over a six-week trial. Twelve children were randomly assigned to receive the drug and 12 children were randomly assigned to receive a placebo. This study used a double-blind controlled research design; experimenters were informed about the children's group assignments upon completion of the study. Psychologists assessed autism symptomology at baseline (prior to the children receiving the drug), after six weeks of treatment, and at a one-month followup assessment.

Results

Statistically significant findings

Repeated-measures ANOVAs revealed no significant between-group difference at any of the times of assessment: pretest ($F = 2.78$, $p > .05$); six weeks ($F = 3.23$, $p > .05$); and followup ($F = 3.56$, $p > .05$). Figure 1 presents the mean scores for each of the three time periods.

Figure 1. Mean improvement scores for drug and placebo groups.



Discussion

The purpose of the present study was to test the efficacy of a new drug for the treatment of autism. It was predicted that, compared with the control group, children who received the drug would demonstrate a significant improvement in their symptoms of autism. Results of the study failed to find support for the efficacy of the drug. Children who received the drug did not differ significantly from children who received a placebo.

References ←

List of relevant studies referenced in the article

Tucker, S., Jones, J., & Martin, M. (2019). The effects of a new drug in the treatment of autism.
Biomedical Research, *6*(1), 23–27.
Vanelli, J. F. (2018). Treating autism: A new era in psychotropic treatment of autism. *Journal of Psychotropic Drugs*, *24*(7),1145–1149.

Appendix D: Sample Worksheets

This appendix contains worksheets that you can use to take notes while reading research articles. The first is a simple worksheet to help summarize the research study. The second is a detailed worksheet that includes specific questions. The third is a quality assessment tool to help you evaluate the merits and relevance of an intervention study for your personal needs. The fourth is a list of considerations to help you think critically about the quality assessment questions presented in the third worksheet.

Simple Worksheet for Reading Research Articles

Title of Article:

Author(s):

Journal:

Date of Article:		Volume and Issue No.		Page Numbers:	

Author Contact Information:

Where Found Article (Website, PubMed, ERIC, Newspaper, etc.: ____________________

Background or Introduction

Methodology

Procedure

Discussion and Conclusion

Detailed Worksheet for Reading Research Articles

Title of Article:

Author(s):

Journal:

Date of Article:		Volume and Issue No.		Page Numbers:	

Author Contact Information:

Where Found Article (Website, PubMed, ERIC, Newspaper, etc.: ____________________

Background or Introduction

What has previous research found about the topic? ____________________

How will this study add to the previous research? ____________________

What are the study's research questions and/or hypotheses? ____________________

Methodology

What type of study? ____________________

Where was the research conducted? ____________________

How many subjects were included in the study? ____________________

What were the characteristics of the subjects? ____________________

What were the inclusion and exclusion criteria for subject selection? ___________________

How were the subjects assigned to groups? ___________________

Procedure

How was the study conducted? ___________________

What kinds of data were collected? ___________________

Are the instruments used valid? ___________________

Have other researchers used the instruments? ___________________

Results

What are the findings? ___________________

Are the findings statistically significant? ___________________

Discussion and Conclusion

How do the authors interpret the findings?

What are the limitations of the study?

How do you interpret the findings?

Are the findings applicable to other people and settings?

Research Study Appraisal Checklist for Parents

1. Was the article published recently?	☐ Yes ☐ No ☐ Unclear ☐ NA
2. Was the article peer-reviewed?	☐ Yes ☐ No ☐ Unclear ☐ NA
3. Were the participants similar to your child?	☐ Yes ☐ No ☐ Unclear ☐ NA
4. Did the study test a treatment/intervention?	☐ Yes ☐ No ☐ Unclear ☐ NA
5. Was the assignment of children to treatments randomized?	☐ Yes ☐ No ☐ Unclear ☐ NA
6. Were the groups of children similar at the start of the intervention?	☐ Yes ☐ No ☐ Unclear ☐ NA
7. Were the groups of children treated the same except for the intervention?	☐ Yes ☐ No ☐ Unclear ☐ NA
8. Were sound measures used to determine if the treatment was effective?	☐ Yes ☐ No ☐ Unclear ☐ NA
9. Was the treatment effective?	☐ Yes ☐ No ☐ Unclear ☐ NA
10. Were the outcomes meaningful or clinically important?	☐ Yes ☐ No ☐ Unclear ☐ NA

If you said "Yes" to five or more questions, this article may be useful for determining if an intervention is effective for your child/family.

Notes:

Adapted from: Critical Appraisal Skills Programme (2018). CASP (Randomised Controlled Trial) Checklist. Available at: https://casp-uk.net/wp-content/uploads/2018/03/CASP-Randomised-Controlled-Trial-Checklist-2018_fillable_form.pdf. Accessed: March 19th, 2019

Appraisal Question Guidelines

There are ways to systematically and strategically evaluate research studies. Here are some considerations to take into account when appraising articles.

1. **When was the article published?** Consider …
    - You want to read the most recent information available about an intervention. Sometimes the most recent information is 5-10 years old, but if the intervention is effective, often more recent studies have been conducted.
    - If it was published before autism diagnostic categorization changed in 2013, the children with autism included may not be the same as the children with autism included in a more recent study.

2. **Where was the article published?** Consider …
    - Is it in a peer-reviewed journal? Papers in these publications undergo a rigorous process of editing and revision from experts in the field.
    - Is it a conference paper, poster, or presentation? These do not undergo a rigorous review process from experts, and may represent preliminary data before a study is completed.
    - Is it in a professional periodical, such as *Autism Spectrum News* or *Autism Parenting Magazine*? These are credible news sources, but the articles do not present original research findings that undergo a review by experts in the field. You may want to go to the original research article.

3. **Who were the participants in the study?** Consider …
    - Are the participants diagnosed with autism? Some studies include children with other disabilities, even if they say "autism" in the title.
    - Are at least some of the participants similar to your child and your family in characteristics such as age, sex, cognitive ability, language ability, socio-economic status, etc.? If not, results may not apply to your child.

4. **Does the study test a treatment or intervention?** Consider …
    - What was changed from the start to the end of the study? Was an intervention conducted? This may include a medication, teaching strategy, parent coaching program, child exercise routine, occupational therapy procedure, etc.

5. **Was the assignment of children to treatments randomized?** Consider …
    - Most studies specify "randomized" in the title, abstract, and methods section if this is true.

- Randomized trials are more rigorous than quasi-experimental (where there is a control group that is not randomly assigned but may be matched on things like age or gender) studies because they make sure groups are equal before starting the intervention. Interpret non-randomized trials with caution.

6. **Were the groups of children similar at the start of the intervention?** Consider …
   - If the trial is randomized, the groups were similar at the start of the trial.
   - If the trial is not randomized, were the groups matched on key characteristics like age, sex, or cognitive level? Were there any important differences between groups? If so, interpret results with caution because treatment differences may be due to differences between the groups rather than the intervention itself.

7. **Were the groups of children treated the same except for the intervention/treatment?** Consider …
   - If there were differences in how groups were treated besides the intervention, you won't know if changes from pre to post are due to the intervention or something else. Interpret these results with caution.
   - Children are usually in educational programs and are constantly learning and changing. It is also unethical to ask families to stop all other interventions to be in a research study. For these reasons, often the control group is called "business as usual" or "services as usual."
   - Sometimes two treatments are compared. One group gets Treatment A and the other gets Treatment B. These studies only tell you if one treatment is more effective than the other. They do not tell you if either intervention is more effective than no intervention. To know if changes are more than developmental, there has to be a control group getting no intervention or "services as usual."

8. **Were reliable and valid measures used to determine treatment effect?** Consider …
   - Did the tests/measures actually measure the target outcome? For example, if the intended outcome of the treatment is attention, did the researchers measure the children's attention at pre- to post-intervention?
   - Were the measures reliable and valid? Do the researchers use "standardized" measures or report things like the internal consistency (ideally > .75) of the measures?
   - If the researchers used an observational or "coding" system, did they collect reliability data on that measure? Ideally > .80.

9. **Was the treatment effective?** Consider …
    - Did the intervention group demonstrate statistically significant changes from pre- to post-intervention compared to the control group on a measure of the target outcome?
    - Were there any major limitations to treatment effectiveness? For example, did some children experience side effects, get worse instead of better, etc.?

9. **Were the outcomes clinically important?** Consider …
    - Were the outcomes relevant to your child and family?
    - Was the intervention feasible for you or one of your child's teachers/therapists/etc. to implement?
    - Was the intervention cost-effective for your family or families like yours?
    - Were the benefits of the intervention worth the costs/time/harms/risks/etc.?

Adapted from: Critical Appraisal Skills Programme (2018). CASP (Randomised Controlled Trial) Checklist. Available at: https://casp-uk.net/wp-content/uploads/2018/03/CASP-Randomised-Controlled-Trial-Checklist-2018_fillable_form.pdf. Accessed: March 19th, 2019