LIFE JOURNEY THROUGH AUTISM:

A PARENT'S GUIDE TO RESEARCH

DANYA INTERNATIONAL, INC.

OAR
ORGANIZATION FOR AUTISM RESEARCH

Life Journey Through Autism:

A Parent's Guide to Research

by

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Dear Fellow Parents and Friends,

From the moment your child is diagnosed with autism, you need to obtain reliable information about this complex disorder. Most parents face a daunting "learning curve" when plunged into this new world of information made up of 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, the parents, to educate ourselves. I personally understand how difficult the period immediately following the initial diagnosis can be for parents seeking answers to their questions; I have a son and daughter with autism, both now in their teens.

When we founded OAR last December, 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. This publication, *Life Journey Through Autism: A Parent's Guide to Research*, is OAR's first addition to this toolkit. It is designed to address the needs of parents of children just diagnosed with autism. I hope that it serves as a useful guide as you and your child begin your own journey.

A project like this cannot be created without hard work from the special friends and supporters OAR is fortunate enough to have. None played a more significant role than our project partner, Danya International, who believed in OAR and donated time, talent, and creative energy to make the Guide a reality. Members of the Danya Team are listed inside. Well done, and thanks.

I offer special thanks to the Autism Society of America - Northern Virginia Chapter, the first parent group to contribute to OAR. Their gift was specifically for this project. Finally, I'd like to recognize the efforts of OAR's staff, Ellen Maidman-Tanner and Mike Maloney, who took the idea and ran with it.

This guide is the first in a series of planned publications that will examine and illuminate various aspects of living with autism. Neither this nor future editions will answer all your questions. This guide is a basic tool that will help you ask questions and investigate issues related to treatment for your child. It is OAR's, and my, sincere hope that it helps you achieve your goals.

I wish you and yours "Godspeed" on your life journey with autism.

Sincerely,

James M. Sack
President

ACKNOWLEDGMENTS

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INTRODUCTION

What is Autism?

Autism is a developmental disorder that appears by 3 years of age and typically involves problems in three major areas of development. Autism diminishes a child's ability to:

- Engage in reciprocal social interactions with others;
- Communicate with others in a manner that is typical of the child's age; and
- Engage in a range of activities and behaviors typical of the child's age and stage of development.

The degree to which these areas of development are affected varies significantly among children with autism. For example, some children with autism have no verbal language abilities, while others have language capabilities within the normal range. This variation in the severity of symptoms is often referred to as the *autism spectrum*. Autism is included in the group of disorders known as the pervasive developmental disorders. This group includes Asperger's syndrome, fragile X syndrome, Rett syndrome, and childhood disintegrative disorder. In addition, there is a closely related, but separately labeled category of disorder called pervasive developmental disorder, not otherwise specified (PDD-NOS). For more detailed information about autism and the developmental profile of children with autism, see the Autism Resources and Recommended Readings sections on pages 35 and 39 of this Guide.

How Many Children Have Autism?

Children with autism are found in all cultures and all social and economic groups. The ratio of boys to girls is 4 boys to every 1 girl diagnosed with the disorder. No definitive study is available on the incidence of autism. Estimated prevalence rates range from a low of 21 to 31 cases of autism per 10,000 children, to a high of one case of autism out of every 1,000 children. Some parent groups report as many as 1.5 million people with autism in the United States alone. Recent studies further suggest that the rates of autism are rising. Disagreement exists within the scientific community about whether or not this is in fact a "true" rate or just the result of greater awareness among medical professionals leading to better diagnosis. Those who believe there is a true increase in the incidence of autism disagree about the cause of this rise. This area of investigation will continue to be one of great interest to both the autism community and the scientific community.

What to Do When Your Child Has Been Diagnosed With Autism

For most parents, the diagnosis of autism is an emotionally challenging and life-changing event. You may feel shocked or overwhelmed by your child's diagnosis. It is natural and understandable for you to 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 concrete options from which you and the professionals on your child's team can choose to help your child. It isn't yet possible to accurately predict how much progress your child will make, but the consensus within the medical community is that early intervention can greatly improve the quality of life for children diagnosed with autism spectrum disorders. This Guide will help you become a better consumer of information about autism.

What a Parent Can Expect Following the Diagnosis

Coping with your child's diagnosis of autism may be difficult—not just for you, but also for siblings, extended family members, and friends of the family. It is not uncommon for parents and other loved ones to experience any number of emotions after the diagnosis, which can range from confusion and anger to hope or despair. Many parents find it helpful to discuss these issues with a counselor or parent support group during the period of adjustment. Support can be found from autism organizations at the local, state, and national levels. You will likely find the most direct support at the local level, with more comprehensive and general autism information at the state and national levels. Contact information for some of the national autism organizations can be found in the Autism Resources section on page 35 of this Guide.

Become an Informed Consumer of Information

You will have to put a great deal of time and effort into becoming a knowledgeable consumer of information as you learn how to evaluate treatment claims. General information on autism can be full of false hope and anecdotal information. From this point on, you will be the primary advocate for your child, so it will be important for you to be able to evaluate your child's needs with the research supporting various interventions for autism. Although much information about autism is available, there is no central resource for it. Furthermore, there can be conflicting opinions about the best methods of treatment to use. You will have to gather information from a variety of sources, including the Internet, mass media, professional journals, reports from conferences and workshops, and educational providers. Networking with other parents and educational or medical professionals will also help you identify sources of information that have been useful to others. What you choose for your child may well end up coming from a number of different sources and a variety of approaches.

A word of caution is in order: *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. An emotional appeal from these promoters can be difficult to resist. Although many promoters of various treatments truly believe in their products or services, few of these fads or miracle cures hold up when scientifically tested.

One of the purposes of this Guide is to provide you with some basic tools for evaluating the validity of these sorts of claims. The same process can be used to evaluate research from more academic sources. This Guide will give you a basic understanding of the purpose of research, how it is conducted, and criteria upon which to judge its value. You will then be better prepared to ask the right questions of your child's doctors, therapists, and teachers about specific interventions when you are faced with new treatment decisions for your child.

HOW TO USE THIS GUIDE

We are living in an age of information. While increased access is mostly beneficial, too much information can also be overwhelming when you are 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 guiding uniform framework; and
- Interpret and apply research findings to their individual situation and needs.

The Organization of the Guide

This Guide is organized into five sections as listed in the Table of Contents. We recommend that you read the Guide thoroughly in its entirety. You can then refer back to a particular section, as needed, to guide you in your search for information on autism.

Glossary

Beginning on page 33, a glossary of terms has been provided to help you understand terminology commonly used in autism treatment and research. Throughout the text, research terms defined in the glossary are marked in **bold** print.

Roster of Autism Organizations

On page 32, a list of Autism Organizations is provided. 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 listed in this section provide you with three types of information: (1) basic information about autism spectrum disorders, (2) an overview of the current state of autism research, and (3) additional information about how to read and evaluate research.

Appendices

- ***Appendix A:* Theoretical Perspectives on Autism:** a summary of theoretical views of autism as a basic source of background knowledge about the differing beliefs about autism.
- ***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:** for five sample types of research.
- ***Appendix D:* Worksheets:** to use for note taking while reading research articles. The worksheets can be copied for repeated use.

HOW TO BE A SAVVY CONSUMER OF SOURCES OF AUTISM INFORMATION

One of your greatest challenges will be sifting through the vast array of information about autism. There are a multitude of autism resources, and it can be very difficult to distinguish between reputable and questionable sources of information. This section will provide you with guidance on where and how to search for resources on autism and autism research. The next section in this Guide is designed to help you learn how to evaluate what you find.

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 general public. In their reports, journalists may cite the author and name of the professional journal in which the research is 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 be sure that the research is interpreted and reported accurately, it is best to get the report “first hand” from the person or persons who conducted the research.

Professional journals report research by the scientists who conduct the studies. The research reported in journals is usually submitted to a process called a **“peer review.”** During a peer review, other researchers read and comment on the quality of the research based on whether it adheres to the ethical and quality standards of the profession. There is a great deal of competition to publish, so the articles that appear in journals are the best of the research being done. This Guide will help you find these “first-hand” reports and determine their applicability to your child’s situation.

Websites

Many Websites cover the topic of autism. Unfortunately, not all Websites are good sources of information. Without some experience or training in searching the Internet, it can be very difficult to discriminate among these Websites. The Websites for the National Autism Organizations provided in the Roster of Autism Organizations on page 35 provide good information on selected topics. Many provide links to other good sites and scientific articles on autism. Some characteristics of Websites that provide avenues to autism research are:

- Provide links to other major autism organizations, academic research institutions, and professional research articles;
- Hosted by government agencies or other non-profit organizations; and
- Clearly cite sources of information.

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 only accessible to the general public through university libraries.

Increasingly, very good online databases are becoming available that can be searched from home-based computers. Three searchable databases available to the general public are: *PubMed* (Medical Publications), *SCIRUS* (for Scientific Information Only) and *ERIC* (Education Resources Information Center).

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

PubMed is located at http://www.pubmed.gov on the Internet.

SCIRUS is maintained by Elsevier Science, the leading international publisher of scientific information, and is available to the general public on the Internet. This Website provides a searchable database of the professional literature and other sources of scientific information on the Internet in a user-friendly format.

SCIRUS is located at http://www.scirus.com on the Internet.

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

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

Online databases are designed to retrieve research articles using the *"keyword"* system. This means that when a word is entered, the online database retrieves all articles that contain that word. The advantage of this system is that it is very easy-to-use. The disadvantage is that this system 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 6,000 articles!

Therefore, the challenge to new users of online databases is learning to narrow a search so that only articles of interest are retrieved. This will usually require some *"trial-and-error"* type practice using these databases. Below are some tips for narrowing an online search using PubMed, SCIRUS, and ERIC.

Tips for Searching PubMed

- Enter keywords such as *"autism"* and *"children"* with the word *"and"* between the words to narrow a search; if too many references are retrieved, another keyword can be added to the search; if too few references are retrieved, a word can be deleted.
- Another way to narrow a search is to choose the "*limits"* option on the home page, which allows a search to be narrowed through publication date, author, population, field, and so forth.
- If an article is related to a topic of interest, click on the "*similar articles"* option, or try entering the author's name in the author field of the "*limits"* option to retrieve similar articles. Authors typically publish more than one article on a topic.

Tips for Searching SCIRUS

- Using SCIRUS, you can enter keywords such as *"autism"* and *"children"* with the word *"and"* between words to narrow a search using the same method as PubMed described above.
- Another way to narrow a search using SCIRUS is to enter a phrase in quotation marks, such as "children with autism." This will retrieve all articles containing the entire phrase.
- SCIRUS also has a "similar articles" option and provides a box of similar search term options on your results page to help you narrow your search.
- When you retrieve an article, you may have to click on the "abstract" link to retrieve the abstract. At the end of the abstract**,** SCIRUS provides a telephone number and email address for contacting the author of the study.

Tips for Searching ERIC

- Choose the *"selected fields"* option on the Search *ERIC Database* page to enter keywords; if too many references are retrieved, add another keyword; if too few references are retrieved, delete a word.
- Choose the *"ERIC Thesaurus"* option on the Search *ERIC Database* page, and then enter search terms in the *"ERIC Wizard*." The *"ERIC Wizard"* converts search terms into similar indexed terms in the thesaurus.
- When an article of interest is located, choose *"author"* in the *"selected fields"* option, and enter the author's name to find other articles written by that author.

When searching online databases, you can also use an asterisk (*) at the end of a root word to pick up all derivatives. For example, autis* will pick up articles that use the keywords *autism* and *autistic*. Asperger* will identify articles that use these terms: Asperger, Aspergers, Asperger's.

Medical and University Libraries

Medical and university libraries contain a wealth of autism research. Those who are fortunate enough to live within commuting distance of one of these libraries can conduct online searches using databases that have been purchased for use by these libraries. These databases are usually more comprehensive than those accessible from home computers.

Medical and university libraries also own large collections of professional journals. The general public is usually welcome to browse these journals and make photocopies of articles to take home; be sure to check the rules at your local library.

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.

Article Location Services

For those who do not live within commuting distance of medical or university libraries, there are several good article location services that will either email, fax, or mail copies of articles to subscribers. It is important to note that there is a fee for these services. Prices of articles typically begin at around $12.00, and users must subscribe to these services to access articles.

- Two good article location services are located on the Internet at: http:/www.ingenta.com and http:/www4.infotrieve.com.
- The ERIC, PUBMED, and SCIRUS databases also provide information for ordering articles.

Contacting Individual Researchers

Once you begin researching, you may discover that a particular researcher has published articles in an area of interest to you. Most autism researchers are very 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 him or her to send reprints of their articles.

Some tips for finding contact information for researchers are:

- In articles published in recent years, contact information, including an email address, is provided on the bottom of the first page of an 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 of affiliation, which will usually be 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. The SCIRUS database described above provides authors' email addresses with the abstract.
- 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 yahoo.com, google.com, or msn.com) will take you to their Website.

A good university locator Website is located on the Internet at:
http://isl-garnet.uah.edu/Universities

UNDERSTANDING THE SCIENCE MODEL

Reading and Interpreting Research

Reading and interpreting research can be a difficult task that will require new skills for the beginner. However, with perseverance and practice, you can gain this expertise and benefit from it. This section is written to give you a basic understanding of the science model before you get started reading the research.

What Can Research Do?

There are two kinds of research: *Basic Research* and *Applied Research*. Both kinds of research are necessary to advance science and apply science to the benefit of society.

- **What is the difference between basic and applied research?**

  Basic research is designed to answer questions about a fundamental or basic problem for the purpose of acquiring knowledge. Biomedical research is often an example of basic research. Research in other scientific areas may overlap between basic and applied research. For example, a researcher may want to answer a question about the relationship between language development and school readiness in children with autism, and then design a basic research study that collects information about this phenomenon.

  Applied research is concerned with applying the knowledge gained through basic research to practical, everyday problems. For example, through basic research, we might learn from the example above that children having autism with verbal skills need less support in an academic setting. Using this information gained through basic research, an applied researcher might design a study to see if a particular program designed to increase verbal skills in preschool children with autism increases their readiness for school.

- **Where are these two types of research conducted?**

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

Studying a Study

A research study is designed to investigate a topic of interest. 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 answer the research question.

Five Basic Types of Research Studies

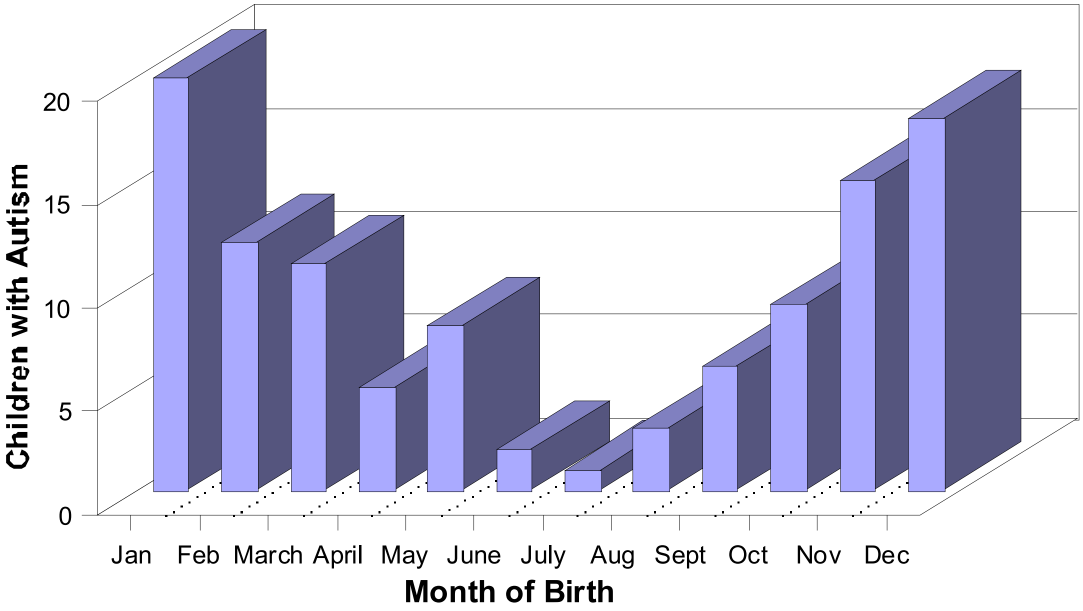
There are five basic types of research studies; each type of study can answer different kinds of questions. The five types (A–E) of research studies are discussed below. Appendix C provides an example of each type of study.

A. **Case Study:** A case study looks at a single **subject** (e.g., a child with autism) or a single **case**, (e.g., a classroom for children with autism). Single-subject studies are typically used in research in therapeutic settings where there is a one-on-one relationship, such as in counseling. Many studies with children with autism, particularly those looking at behavioral treatments, use a single-subject design (a subset of which falls into a specialized category referred to as a "single-subject experimental design").

- The *advantage* of a case study is that a lot of information can be gathered 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 be readily **generalized** to other people or other cases in other situations or other settings.

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 *month of 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.

Figure 1: Correlational Study: Children With Autism and Month of Birth

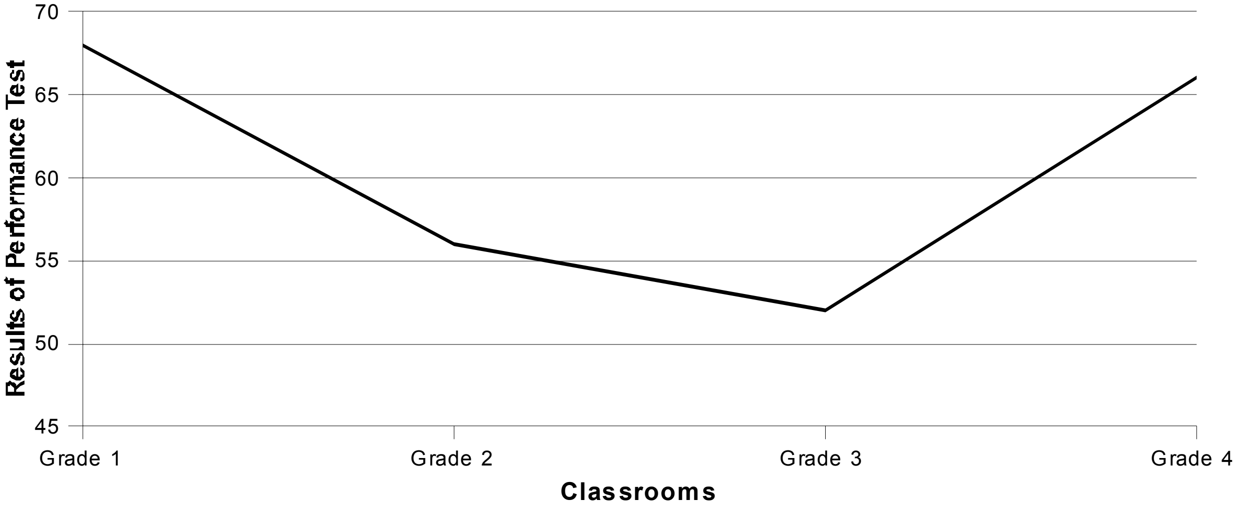


Although this graph shows a relationship between cases of autism in one community and month of birth, we cannot make the assumption that a winter birthday causes autism. It may be the case that some other variable that we have not considered (such as illness in the mother) is having an effect on the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

- 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 or inclusive classrooms. The best research design for answering this question would be to follow one cohort of children with autism who have 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* is that longitudinal studies require a long time to complete. (Note in the example in Figure 2, the study took 4 years to complete).

D. **Experimental Studies:** Experimental studies are used to study cause and effect. Experiments are controlled so that one variable is **manipulated** by the researcher to determine its effect on other variables.

In experimental designs, participants are **randomly assigned** to receive either the intervention (the experimental group) or to a **control group.** The control group completes all the same steps as the experimental group, except the intervention that is under investigation. Therefore, if the study is well controlled, the differences between the experimental and control groups at the end of the study will be 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 this example, the variable that is manipulated by the researcher is the "*educational program.*" In this study, subjects in the experimental group would receive the new program, while subjects in the control group would receive a standard program.

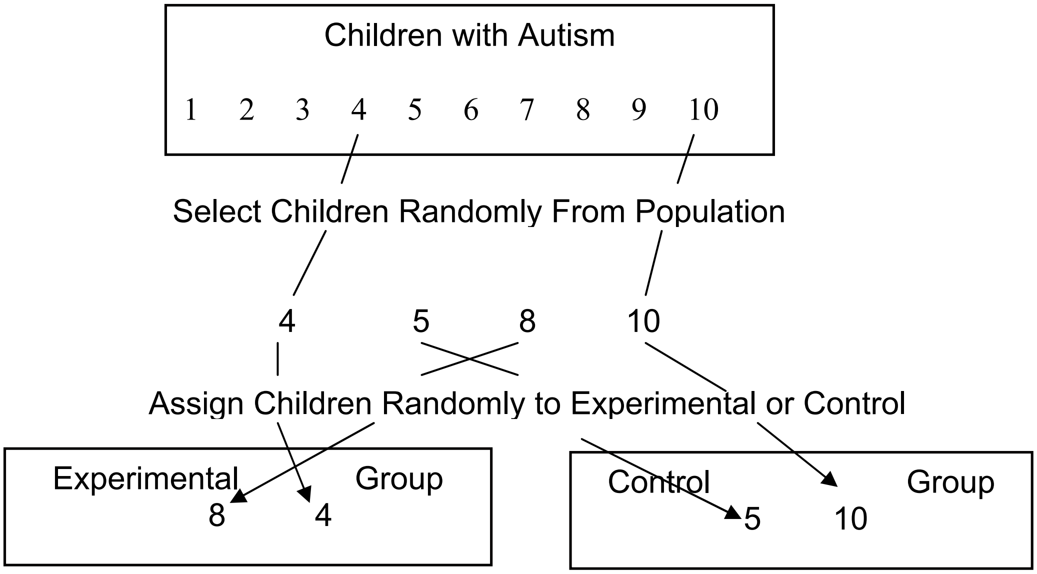
The purpose of the study would be to determine if the test scores of students receiving the new method would be higher than the scores of the students receiving the standard method.

- 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.

A cornerstone of experimental research is the concept of randomization. Participants in the experimental study are randomly assigned from the population to either the experimental or the control group. This assignment is done randomly 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.

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

Figure 3: The Randomized Experimental Method of Research



In both randomized experimental 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 to guard against **researcher expectations** about intervention or treatment. That is, if either the participant or the researcher expects to get better because they know they are getting treatment, they may actually get better, 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.

- 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 randomized experimental studies; that is, the results of the study cannot always be generalized to a real-life setting.

A UNIFORM FRAMEWORK FOR EVALUATING RESEARCH STUDIES

There is a standard format used for reporting research in most professional journals that publish research studies. This section will help you read and analyze research articles by providing you with a framework for evaluating them. Research articles are typically organized into six sections in the following order: (1) Abstract, (2) Background or Introduction, (3) Methods or Methodology, (4) Results, (5) Discussion, and (6) References. This is the most common format for reporting research. You will probably find that some journals use a different format; nevertheless, you can still use this standard format as a guide for evaluating a research article.

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 each of the five sections of the article and usually includes the following key points:

- The purpose of the study, or why the authors think it was important to conduct the study
- Information about the participants in the study; their ages, ethnic background, etc.
- The 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 can be printed from the Internet and 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 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 done in isolation; it is connected or related to other research. Therefore, research articles begin by summarizing previous research on the topic of interest. The purpose of summarizing previous research is to provide a framework or 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 provided in the references section at the end of the article. If during your reading, you come across a previous study that sounds interesting, you can get the full reference to the article in the reference section at the end of the article.

An Example of Background Information

In a previous study, Jones, Meyers, and Klein (2000) found that children with autism take longer to learn new tasks than other children. This finding has been confirmed in numerous other studies (Brown and Rogers 1989; Roberts 1999; Williamson, et al. 1995).

After summarizing previous research, authors will state how the study conducted in the present article adds to what has already been done.

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

Often (but not always), authors will 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. 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 than one research question. 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

Children with autism who receive early intervention 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 in this section include:

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

Sometimes, the authors will tell the reader what type of study they used. Often, however, the type of study will not be explicitly stated, but clues will be evident in the study design. See Appendix C for specific examples of 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 in this section include:

- *How many subjects were in the study?*

With the exception of case studies that 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 used, the more **reliable** the results of the study.

However, it is also important to bear in mind that studies that conduct research with people with disorders such as autism will 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 affected to every one girl. Therefore, we would expect a good 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, this can be difficult. Many studies are conducted in laboratories or special schools where participants volunteer to participate in the study. In this case, 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, research studies should include all eligible participants. However, there are circumstances when certain people might need to be excluded. For example, a study might want to look at characteristics of boys and not girls. Therefore, 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. Good research studies "randomly assign" participants to groups. **Random assignment** is a lot like "flipping a coin." It means that each participant has an equally likely chance of being in any one group. The purpose of random assignment is to guard against **bias** being introduced into a study; that is, to ensure that there are no differences in the basic characteristics of participants in any one group as compared with any other group.

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 another person to recreate the study exactly, given they had the equipment or skills to do so.

- *What kinds of data were collected?*

The procedure section should also give specifics about what kinds of data were collected from the participants in the study, such as measures of knowledge or behavior.

A good study collects sufficient data to 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 will 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 with percentage points above .75 are considered to have good validity. However, a lower score may be considered acceptable depending on whether or not 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. Authors should refer to other studies that have used the same instrument by referencing 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 this study, the authors should give a lot of detail about the measure, as well as an explanation about why it was chosen for use in the current study.

Results

The results section explains the statistical analyses of the data used in the study and presents the findings of the analyses in three formats: (1) narrative (written in text), (2) graphic (depicted in graphs), 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 a study. The average layperson (and even some researchers!) will be unable to evaluate the statistical methods used in conducting research. Therefore, the best strategy for evaluating the findings of the study may be for you 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, the reader can get a general idea if one group scored much 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). There is an asterisk after this score to show that the difference is **statistically significant**. On the spatial skills test, the experimental group still scored higher than the control group (70 vs. 68), but this difference isn't as large and therefore isn't 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 in a graphic format (often figures are presented as bar graphs, as illustrated in Figure 1 or line graphs as illustrated in Figure 2). By looking at the exhibits, the reader can see if there is a general pattern in which one group differs from another.

Not all studies present the findings in both tabular and/or graphic formats. Therefore, sometimes the reader will have to interpret the findings as best they can by reading the text. When reading the text, look for mean differences between groups.

- ◆ *What do the findings mean?*

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

> The discussion section will explain the findings of the study in terms that are more easily understandable.

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 the findings?*

The discussion section should begin with a summary of the findings of the study. 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.” This is 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 the 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?*

In the discussion section, 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 limited to a laboratory setting. The researchers may end this section by talking about what research still needs to be done 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. In the references section, the authors list all research studies that they cited in the text. You can find full references to these articles in this section. If you want to look up a reference on one of the online databases, you can enter the author’s name in the author field or the title in the title field.

Beware of a Conflict of Interest

As an educated consumer of information, it is important for you to be aware that researchers may sometimes be 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 increased pressure to find evidence that supports the use of these products. Therefore, it is always wise to investigate the source of funding behind the research. You can find this information in the research article. 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.

Conclusion

In general, be skeptical when evaluating the 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 there are many knowledgeable parents and professionals in the autism community with whom you can discuss misgivings and questions about the research.

In the final analysis, it is up to you to decide if a particular study makes sense, or has what researchers refer to as **face validity**. A parent is the leading expert when it comes to his or her own child. If something doesn't "ring true" to you, trust your own instincts and make your own assessment.

THE CURRENT STATE OF AUTISM RESEARCH

Biological and Genetic Research

Throughout the later part of the 20th century, researchers conducted biological and genetic research in autism. The National Institutes of Health (NIH), headquartered in Bethesda, Maryland, just outside of Washington, DC, is the world's leading research center. In 1997, the NIH initiated the *Collaborative Programs of Excellence in Autism* (CPEA). The CPEA is a collaborative research effort between the following five Institutes of NIH:

- National Institute for Child Health and Human Development (NICHD)
- 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)

A list of autism research projects currently being funded by the National Institute for Child Health and Human Development can be found at:
http://www.nichd.nih.gov/autism/projects.cfm

The main goal of the *Collaborative Programs of Excellence in Autism* is to support research programs aimed at finding biological causes and genetic markers of autism. More information about this program can be found on the NICHD Website at http:www.nichd.nih.gov/autism/cpea.cfm. At the time of publication of this Guide, the CPEA was funding more than 100 research-based projects in autism.

There are several private autism organizations dedicated to biomedical research. Their efforts over the last decade have heightened awareness and support for autism research into "cause and cure." The most prominent of these organizations are listed in the box below. More information about these organizations can be found in the Roster of Major National Organizations, Foundations and Resources beginning on page 35.

Prominent Autism Organizations Dedicated to Funding Biomedical Research:

- Autism Autoimmunity Project (AAP)
- Autism Research Institute (ARI)
- Cure Autism Now (CAN)
- National Alliance for Autism Research (NAAR)

Biobehavioral Research

Another area that shows great promise is biobehavioral research. The development of Positron Emission Tomography (commonly referred to as the *PET* Scan), in the latter part of the 20th century provided researchers with a technique for studying the brain *in action* during mental processing. The development of this tool has allowed researchers to study how people with autism process information. By comparing the brain activity of people with autism with typical people, researchers are now beginning to understand more about these differences in mental processes. Moreover, because differences in mental processing can cause behavioral differences, the PET Scan is also helping researchers understand more about behavioral differences in people with autism.

Intervention Research

Scientists doing applied research often look at different types of interventions that have been used to help individuals with autism learn new skills, behaviors, and strategies. Many types of interventions are being created, and high-quality, controlled research is needed to determine which types of interventions show the most promise.

The Organization of Autism Research (OAR) is a national private foundation dedicated to funding applied autism research.

Beware of Unsubstantiated Claims of Success: No Miracle Cures Exist!

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

- Newspaper or magazine articles 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 should include searching in a reputable database to see if anything has been published about the treatment, and contacting the people making these claims and asking for literature about their work. As a savvy consumer of information, you now know how to evaluate this information! It is important to look into these claims to see if they are supported by well-designed research. A good place to begin is the NICHD autism Website.

If there is no research supporting claims of “miracle” cures, then they should be viewed with healthy skepticism.

DIRECTIONS FOR FUTURE RESEARCH

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, there are important environmental factors that 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. Traditionally, it has been difficult for researchers to design a research study that can determine how much of a trait is determined by what we inherit through our genes and how much of the trait is influenced by our environment. The decoding of the human genome at the beginning of the 21st century has ushered in a new era in research. Now that the entire human genome has been mapped, autism researchers are beginning to be able to design research that will help us understand the complex interplay between genes and the environment in determining autistic behavior.

Early Diagnosis

Until very recently, it was difficult to diagnose a child with autism before the age of 3; in the past, many children were not diagnosed until school age. In 1998, the NIH sponsored a conference to establish standardized assessment tools for the early diagnosis of autism spectrum disorders. There are now published studies that confirm that early diagnosis is vital to the future of children with autism, and assessment tools have been developed to help health care professionals make these diagnoses at younger ages.

Early Intervention

Related to early diagnosis is early intervention. According to a report from the National Research Council, prompt educational intervention is key to helping children with autism learn the skills needed for self-care, school success, and community functioning. There is, at present, some research to support early intervention based on the principles of Applied Behavioral Analysis (ABA), but beyond this, the evaluation of intervention lacks scientific validation. On September 5–6, 2002, the NIH held a workshop in which the leading researchers in psychosocial interventions for autism discussed their plan for conducting more rigorous scientific research into the best methods of early intervention.

Educating Children with Autism

Before the 1990's, children with autism were educated in separate special education classrooms. With the passage of several education mandates, however, increasing numbers of children with autism are now being educated in classrooms with their typically developing peers. Such settings offer many educational advantages to children with autism; they also present challenges for them, their teachers, and classroom peers. In 2001, the National Research Council published a comprehensive report based on the findings of an appointed *Committee on Educational Interventions for Children with Autism*[1]. This report, *Educating Children With Autism*, has set the stage for increased research into the education of children with autism.

The Report from the National Research Council on educating children with autism can be obtained on the Internet at: http://www.nap.edu.

Social and Economic Support Systems for People With Autism

Most individuals with autism will require some degree of support throughout their lives. The intensity of this care will vary from person to person: it may range from 24-hour supervision to monthly case management. Research is needed on how to provide the best support possible to individuals with autism. Many issues, including the education and credentialing of professionals working with individuals with autism, housing options, and how to access medical care, require systematic attention.

Jobs for People With Autism

Only limited literature exists on employment for persons with autism. With the right training and support, persons with autism can and should be employed. To this end, additional research is needed regarding issues such as how best to assess "job match" for individuals with autism, what employer variables are associated with more positive employment outcomes, and to what extent co-worker training may be integral to success in workplace settings.

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.

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[1] National Research Council. *Educating Children With Autism*. Washington, DC: National Academy Press, 2001.

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 have become more prominent, well-designed research into this particular area has become more critical.

Conclusion

Research is helping solve the puzzle of autism. However, many unanswered questions and issues remain that need further investigation. It is our hope that this first document in a series of publications will serve to provide families affected by autism with the tools needed to explore and evaluate both the published research as well as the cumulative body of research that will come out of future studies.

GLOSSARY OF RESEARCH TERMS

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 know 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 “cohort” refers to a group of individuals identified by a common characteristic, which is studied over a period of time as part of a scientific investigation.

Control: “Control” refers to the condition or group that does not receive treatment.

Cross-section: A “cross-section” consists of 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.

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 observational coding scale.

Manipulation: In an experiment, “manipulation” occurs when a researcher does something to one variable to see if it affects another variable.

Mean: The average score for a group of participants.

Participant expectations: “Participant expectations” refers to things that people expect to happen when they participate in a research study.

Peer review: Academic and scientific journals generally require that articles be submitted to a committee of one’s peers to review for scientific merit and accuracy before appearing in a journal.

Placebo: “Placebo” refers to a pretend treatment that participants believe is the real treatment, such as a sugar pill.

Random assignment: Participants in a study are assigned to be in either an experimental group or a control group using a method similar to “flipping a coin,” 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.

Researcher expectations: “Researcher expectations” refers to things 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 percent.

Subject: Someone who participates in a study.

Validity: In research, “validity” refers to something being what it is supposed to be, and not something that it shouldn’t be.

Variables: The thing or things that are being studied.

ROSTER OF MAJOR NATIONAL AUTISM ORGANIZATIONS, FOUNDATIONS, AND RESOURCES

Many autism and disability organizations can be found across the country, from small local support groups to broad-based national organizations. Below is a partial listing of national organizations whose Websites provide useful information to families living with autism. In addition, there are many excellent organizations at the statewide and regional level that can help families with information, resources, and lists of local doctors, clinics, and schools. They are too numerous to list here but can be found through searches on the Web or through information provided by some of the organizations listed here.

Autism Autoimmunity Project (AAP)
http://www.autismautoimmunityproject.org
P.O. Box 293144
Davie, FL 33329
1-800-939-8227

Focus: Funds independent research addressing immune and immunogenetic abnormalities in autism.

Autism Coalition for Research and Education (ACRE)
http://www.autismcoalition.org
181 Westchester Avenue
3rd Floor
Port Chester, NY 10573
1-914-935-1462

Focus: Funds research and education projects of existing autism organizations.

Autism Society of America
http://www.autism-society.org
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
1-800-328-8476

Focus: National advocacy. Membership organization with numerous local chapters.

Cambridge Center for Behavioral Studies
http://www.behavior.org
336 Baker Avenue
Concord, MA 01742-2107
1-978-369-2227

Focus: Applied behavior analysis methods of autism intervention. Good Website for learning more about this educational approach.

Cure Autism Now Foundation
http://www.canfoundation.org
5455 Wilshire Blvd., Suite 715
Los Angeles, CA 90036
1-323-549-0500
1-888-828-8476

Focus: Biomedical research and national advocacy.

The Dan Marino Foundation
http://www.danmarinofoundation.org
P.O. Box 267640
Weston, FL 33326
1-954-888-1771

Focus: Funds integrated intervention services for children with special needs - medical, emotional, and/or behavioral.

The Doug Flutie, Jr. Foundation for Autism, Inc.
http://www.dougflutiejrfoundation.org
P.O. Box 767
233 Cochituate Rd., 2nd Floor
Framingham, MA 01701
1-866-328-8476

Focus: Funding for research and programs that help families in the autism community.

MAX Foundation
http://www.maxfoundation.org
P.O. Box 22
Rockville Centre, NY 11571
1-516-763-4787

Focus: Promotes special education awareness. Website provides a comprehensive listing of major autism organizations and informational autism sites.

National Alliance for Autism Research
http://www.naar.org
99 Wall Street, Research Park
Princeton, NJ 08540
1-609-430-9160 or 1-888-777-6227

Focus: Biomedical research and national advocacy, particularly related to research.

National Information Center for Children and Youth with Disabilities (NICHCY)
http://www.nichcy.org
P.O. Box 1492
Washington, DC 20013
1-800-695-0285

Focus: National information center that provides information on disabilities and disability-related issues. This is a site rich with resources, including conferences, state organizations, and information.

Organization for Autism Research
http://www.researchautism.org
2111 Wilson Boulevard, Suite 600
Arlington, VA 22201
1-703-351-5031

Focus: Applied research and feedback on research to the autism community.

The National Institute of Child Health and Human Development Autism Site
http://www.nichd.nih.gov/autism

Focus: The goal of this site is to provide easy access to the most current information about NICHD research projects, publications, news releases, and other activities related to autism and similar disorders.

Recommended Readings

Below is a sampling of some excellent books 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.

Readings on Autism

Alberto, P.A. & Troutman, A.C. (2002). *Applied Behavior Analysis for Teachers*, 6th ed. Upper Saddle River, NY: Merrill Prentice Hall. See pages 167–226 in this book for information on single subject experimental research designs.

Attwood, T. & Wing, L. (1998). *Asperger's Syndrome: A Guide for Parents and Professionals*. London, England: Jessica Kingsley.

Baron-Cohen, S. & Bolton, P. (1994). *Autism: The Facts*. New York: Oxford University Press.

Cohen, D.J. & Volkmar, F.R. (Eds.) (1997). *Handbook of Autism and Pervasive Developmental Disorders.* Toronto: John Wiley & Sons.

Cohen, S. (2002). *Targeting Autism: What We Know, Don't Know, and Can Do to Help Young Children with Autism and Related Disorders*. Berkeley, CA: University of California Press.

Harris, S.L. (1994). *Siblings of Children with Autism: A Guide for Families.* Bethesda, MD: Woodbine House.

Mesibov, G.B., Adams, L.W., & Klinger, L.G. (1998). *Autism: Understanding the Disorder*. New York: Plenum Press.

National Research Council (2001). *Educating Children with Autism*. Washington, DC: National Academy Press.

Powers, M. (2000). *Children with Autism: A Parent's Guide (2nd ed.)*. Bethesda, MD:Woodbine House.

Siegel, B. (1998). *The World of the Autistic Child: Understanding and Treating Autism Spectrum Disorders*. New York: Oxford University Press.

Sigman, M. (1997). *Children With Autism: A Developmental Perspective*. Cambridge, MA: Harvard University Press.

Wolfberg, P.J. (1999). *Play & Imagination in Children with Autism.* New York: Teachers College Press.

Readings to Assist With Reading and Interpreting the Research

Editors of the American Heritage Dictionaries (Ed.). (1998). *Medical Dictionary: A Concise and Up-to-Date Guide to Medical Terms*. Houghton Mifflin Company.

Girden, E.R. (2001). *Evaluating Research Articles From Start to Finish*. Thousand Oaks, CA: Sage Publications.

Locke, L.F., Spirduso, W., Silverman, S.J., & Silverman, S.M. (1998). *Reading and Understanding Research*. Thousand Oaks, CA: Sage Publications.

Mann, T. (1998). *The Oxford Guide to Library Research*. New York: Oxford University Press.

APPENDICES

APPENDIX A

THEORETICAL PERSPECTIVES ON AUTISM

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Autism was identified in the middle of the 20th century. In 1943, Leo Kanner, a child psychologist who worked at Johns Hopkins University, first identified the disorder based on a group of children who had very similar problems in the three major areas of development: social interactions, communication, and activities and interests. Kanner believed that autism was a type of social disability, present at birth, with biological origins. Since Kanner's identification of the disorder, there have been many views about the causes of autism. To understand where these views come from, it is important to understand the theoretical roots behind each view. Each of these views differs on the belief of the role of nature versus nurture in the expression of autism. A brief overview of each theory is presented below.

It is important to bear in mind that theories are not fact, and each should be viewed as only one perspective of autism. Therefore, it is important to understand that there is no one "right" theory or point of view.

The Psychoanalytic View

The psychoanalytic view of autism is based on the theory of Sigmund Freud, which was introduced in the 1930s and 1940s in the United States. According to this theory, autism is caused by a child's reaction to his family environment. In the 1960s Bruno Bettleheim, a child psychiatrist, wrote the "The Empty Fortress," a book about autism written from the psychoanalytic view that popularized the term "refrigerator mother." According to this theory, the cause of autism was believed to lie in a mother's unconscious rejection of her child. This theory was never supported by empirical research and has since been discredited by the professional autism research community.

The Behavioral View

The behavioral view of autism is that all behavior can be understood as a function of the stimulation the individual responds to in the environment. Behavior is shaped by its consequences; rewards increase the frequency of a behavior, and punishments decrease the frequency of a behavior. An example would be when a child with autism, who has no language, requests something from a parent using a gesture and receives it. The nonverbal behavior has been reinforced because the child was rewarded with what he wanted. Most educational programs for children with autism have a large component based on a behavioral approach. A behaviorist would most likely conduct research on interventions that target behavior change and new learning.

The Cognitive View

The cognitive view of autism is based on the “Theory of Mind.” According to this theory, people with autism think differently than typical people. Specifically, they do not understand that people have different points of view and internal thought processes. Rather, they believe that everyone views things the same way that they do. A cognitive researcher who adheres to a “Theory of Mind” view would most likely conduct research designed to help children with autism understand other points of view and promote more sophisticated thinking processes.

The Biological View

The biological view is that autism is a biological disorder with psychological and behavioral symptoms. Many different theories fall within the biological view of autism, ranging from genetics to different brain anatomy to viral infection. What biological researchers all have in common is the belief that autism is caused by something in the child’s biological make-up and that the psychological and behavioral symptoms are a result of the child’s biology. Biological interventions are based on changing the child’s physiology, either through medication, diet, or targeting physiological systems such as auditory processing.

The Environmental View

The environmental view holds that while genetics play an important role in autism, the emphasis should be placed on environmental influences that trigger the expression of genes. According to an environmentalist, a child may be born with a predisposition to autism, but for the disorder to become expressed, the child must come into contact with an environmental agent to which the child has an increased sensitivity. In designing an intervention, environmental researchers would look to eliminate the environmental factors that could trigger the expression of autism.

Remember – Theory Informs Research

Each study is written by an author with specific beliefs about autism. This theoretical stance will influence what research question he asks, which variables he studies, what type of research he chooses, and what conclusions he draws about the findings of the research.

APPENDIX B

PARTICIPATING IN RESEARCH STUDIES

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Two types of research studies actively recruit children with autism as participants: randomized experimental and clinical trial studies. Both of these types of studies require voluntary participation. The decision to participate in research studies is a personal decision. If you decide that you would like to have your child participate, some important points should be considered.

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 review process that the study had to undergo. Be sure that the research is being conducted in a controlled environment that is committed to the protection of participant rights. Generally, studies conducted at universities and medical institutions must receive 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.

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; if you will 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 Section 2? 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 be sure you understand whether or not you will be offered 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 "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 With Human Participants

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

- *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 are going to ensure the confidentiality of you and your child's identity.
- *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 <u>written</u> informed consent for participation.

If you are not informed of any of these aspects of the research, <u>do not</u> participate in the study.

APPENDIX C
SAMPLE RESEARCH ARTICLES

These sample research articles are fictional and used for illustrative purposes only.

A Sample Case Study

Journal of Collaborative Autism Research (2000), 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.

previous research cited

Introduction

Parents often report sleep problems in children with autism (Callahan 1987; Rogers and Brown 1992). Moreover, research reveals that problems in sleep may be affected by seasonal changes (Robins, Williams, Jones, and Miller 1999). 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 in the form of a statement of

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.

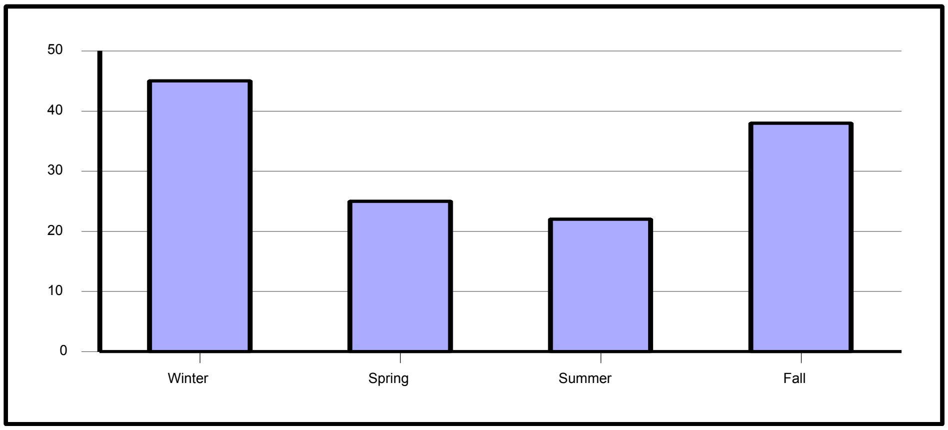
The sleep problem scores for each of the three month seasons are presented in Table 1.

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



Author's interpretation of the findings of the study.

Discussion

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, and Winthrop 1991; Price 1995). [*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.

A Sample Correlational Study

Journal of Family Research (1999), 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 authors

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 non-scientific 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 non-scientific professions. The findings of the study are discussed in terms of their implications to future research.

Introduction

It is well-established that there are significantly more boys diagnosed with autism than there are girls, with ratios consistently reported at four boys to every one girl (Billings, Dweck, Klinger, & Newman, 1998). There is less evidence that the transmission of the disorder follows the path from father to son. There have been anecdotal reports of higher rates of certain "scientific" traits and tendencies in fathers of boys diagnosed with autism than fathers of typical boys (Phillips, 1994; Ziegler, 2000), but to date, there have been no research studies seeking 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 non-scientific professions}.*

Research question

previous research cited

Method

Subjects

The subjects were 498 men in scientific professions (75% Caucasian, 10% African American, 15% Asian) and 658 men in non-scientific 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.

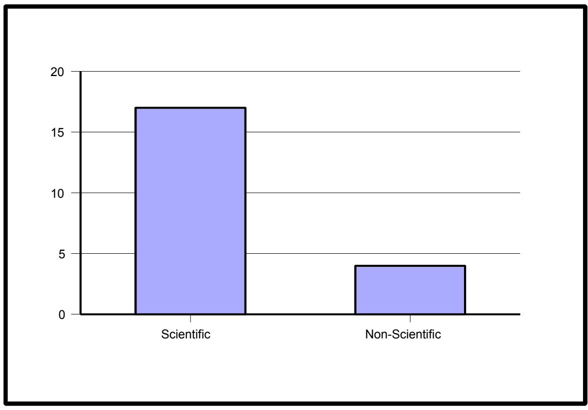
Procedure

Surveys were mailed to the homes of 2000 men selected at random from scientific corporations and 2000 men randomly selected from non-scientific 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. A total of 498 men in scientific professions and 658 men in non-scientific 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 non-scientific professions.

Figure 1: Percentage of Men with Sons Diagnosed with Autism in Scientific and Non-Scientific Professions



cussion

The present study sought to determine if fathers in scientific professions were more likely to have sons diagnosed with autism than fathers in non-scientific professions. The results of a survey sent to a random sample of men in scientific and non-scientific 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 fathers of typical boys (Phillips 1994; Ziegler 2000). 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.

A Sample Longitudinal Study

Journal of Longitudinal Autism Research (1998), 4(5), 138-145.

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

A one year follow-up 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). Those children who received a clinical diagnosis of ASD were re-evaluated 1 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, 2001). Because a number of 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, 1997; Carlson, 1996; Rogers & Hammerstein, 1999). However, some child development specialists fear that a diagnosis of autism made before the age of three years may be premature and children diagnosed before the age of three may not meet the same diagnostic criteria after age three (Howell, Musselman, Treman, et al., 2000). *{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 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, 1995) and Behavioral Rating Scales (Jones & Harper, 1989) at two points in time. All the subjects were evaluated at the time of initial intake (Time 1). Those children who received a clinical diagnosis of ASD were re-evaluated 1 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 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 early diagnosis of ASD argument (Blackman 1997; Carlson 1996; Rogers & Hammerstein 1999). The independent assessments of clinicians conducted when the children were under the age of three and one year later were highly consistent. *{Thus, based on the results of this study, we would advocate early diagnosis of ASD.}*

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

A Sample Experimental Study

Journal of Autism Intervention Studies (1992), 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 pre-school 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 had 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 post-test. This 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 would seem 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 and Howell 1989; Miller 1990). The results of these studies were mixed. While the Jenkins and Howell (1989) study showed some benefits, the Miller (1990) 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, as 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 three and five years. There were 32 boys and 6 girls. There were 31 Caucasian, 4 African American, 1 Asian, and 2 Hispanic children.

Procedure

Four schools were randomly assigned to receive 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 consisted of 22 children and the control group consisted of 16 children. The intervention consisted of group exercises in correcting negative behavior, conducted every day for three weeks. The control group received no exercises.

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 follow-up 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 that there was 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 post-test. 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	Post-test
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, as 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.*]

Authors' conclusions based on findings

APPENDIX C

A Sample Clinical Trials Study

Journal of Clinical Trial Studies in Autism (1997), 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 children taking a placebo, the differences were not significant. Future research is needed to further investigate the effects of this drug.

Introduction

previous research cited

Many psychotropic drugs have been tested for their efficacy in treating the symptoms of autism (e.g., Tucker, et al., 1992; Vanelli, 2001). However, to date, none has proved 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. 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.

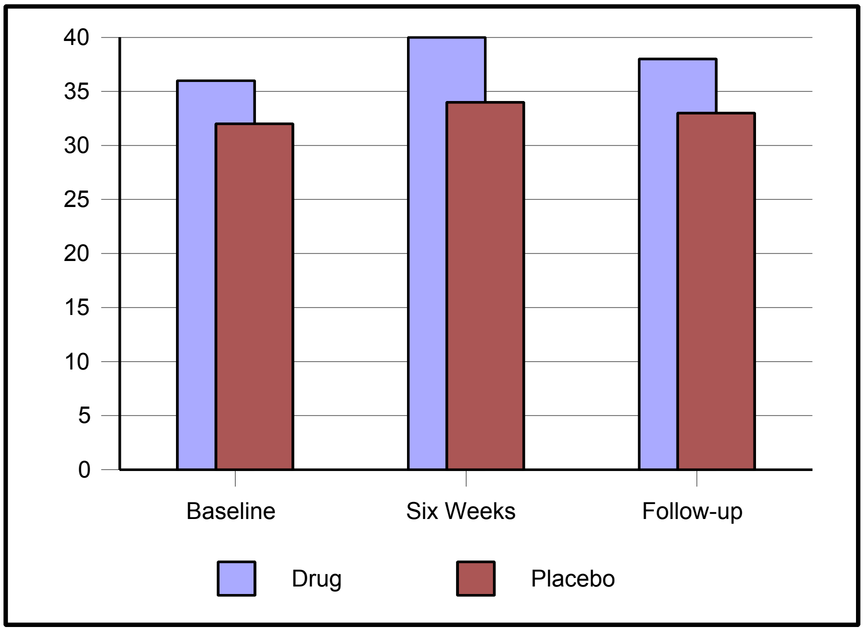
Psychologists assessed autism symptomology at baseline (prior to receiving the drug), after six weeks of treatment, and at a one-month follow-up assessment.

Statistically significant findings

Results

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 Follow-up (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, as 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

Tucker, S., Jones, J., & Martin, M. (1992). The effects of a new drug in the treatment of autism. *Biomedical Research,* 6(1):23–27.

Vanelli, J. F. (2001). Treating autism: A new era in psychotropic treatment of autism. *Journal of Psychotropic Drugs,* 24(7):1145–1149.

APPENDIX D

SAMPLE WORKSHEETS

Appendix D contains worksheets for taking notes while reading research articles. There are two versions of this worksheet – a detailed worksheet for those who like to take more detailed notes, and a simple worksheet with minimal details for those who like to take more streamlined notes.

Simple Worksheet for Reading Research Articles

Title of Article:

Author(s):

Journal:

Date of Article:		**Volume No.**		**Page Numbers:**	

Author Contact Information:

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

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Background or Introduction

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Methodology

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Procedure

Results

Discussion and Conclusion

Detailed Worksheet for Reading Research Articles

Title of Article:

Author(s):

Journal:

Date of Article:		**Volume 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 hypotheses?

Methodology

What type of study?

Where was the research conducted?

How many subjects were 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 summarize the findings?

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?

ORGANIZATION FOR AUTISM RESEARCH

OAR's Values

To understand OAR is to understand the spirit in which OAR operates. The following principles underlie everything OAR does. We provide this information as a statement of values and a simple means of "getting to know" OAR for anyone unfamiliar with the organization, its leadership, volunteers and staff.

---

1. **The Community Comes First.** OAR exists to serve the autism community. OAR's policies, programs, decisions, and actions place the best interests of the community-at-large ahead of any other group or personal interests.

2. **Practical Research for the Living.** OAR's focus is on research that yields results and findings that have practical applications for those living with autism today--the children and adults on the autism spectrum, their families, and all those who give them love and support.

3. **Self-Advocacy/Self-Determination.** OAR understands that some persons with autism are capable of representing themselves and achieving a high degree of independence in life. OAR will give self-advocates roles and a voice in its Community Council.

4. **Family Focus.** Autism has a direct and often varying effect on each member of the family. OAR views the disorder in this broader context and will encourage research that illuminates and examines the impact of autism within the family dynamic.

5. **Quality Information.** OAR will strive to provide high quality, useful information, free of bias, and appropriately referenced whenever possible.

6. **Taking a Stand.** OAR will not hesitate to speak on matters of importance to the autism community, particularly on research matters that fall within the collective expertise of OAR's Scientific Council or the scope of any of OAR's studies.

7. **Free Access for the Community.** Parents and families pay enough**.** OAR will not assess dues or charge any access fees. OAR will raise money in order to provide members of the autism community free access to OAR's information resources.

8. **"By the People, for the People."** OAR holds itself accountable to the autism community. In that vein, OAR believes that its best measure of success will come in the form of feedback from those OAR serves. Those inputs will help OAR maintain focus and direction.

9. **One Cause, Many Good Organizations.** There are many good autism-related organizations. OAR believes that there is strength and purpose in those numbers, particularly for a cause as broad and complex as autism. OAR will collaborate whenever and wherever it best serves the autism community and the mutual objectives of any other organization and OAR.

10. **Opening More Doors.** Autism abounds with personal stories of love, determination, and inspiration emerging from even the most dismal circumstances. Full of humor and distinctively lacking in self-pity, various authors acknowledge that life has challenges more difficult than autism, and they build on the theme "When one door closes, another opens." OAR will complement this rich environment by opening doors to the serious issues in its mission with spirit, enthusiasm, and optimism.

"Research and resources that help families today!" www.researchautism.org

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 guiding uniform framework
- Interpret and apply research findings to their individual situation and needs